



# **NATIONAL CARER STRATEGY CONSULTATION: ONLINE INTERVIEWS**

Prepared for the Australian Government  
Department of Social Services  
August 2024



**AN AUSTRALIA THAT VALUES AND SUPPORTS ALL CARERS**

## ABOUT CARERS AUSTRALIA

Carers Australia is the national peak body representing the diversity of the 3 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.<sup>1</sup>

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 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.

Our carers are diverse and include those who:

- have their own care needs
- are in multiple care relationships
- have employment and/or education commitments
- are under 25 years (young carers)
- are 65 years and over
- identify as Aboriginal and Torres Strait Islander
- are from culturally and linguistically diverse backgrounds
- identify as Lesbian, Gay, Bisexual, Trans and gender diverse, Intersex, Queer, Questioning and Asexual (LGBTIQ+)
- live in rural and remote Australia
- former carers (no longer in a caring role), and
- live with a disability.

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 – [United Nations Universal Declaration of Human Rights](#)<sup>2</sup>).

### Acknowledgment of Country

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.



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

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

# EXECUTIVE SUMMARY

*"My biggest passion is how underpaid we really are. As (a) carer I'm not able to work anymore, so there goes my ability to make any income. And all the work that support workers should be doing, I'm doing. And I experience care burnout."*

(Online Workshop 2)

Flexibility, better navigation and assistance, recognition, and planning for the future featured heavily in the Carers Australia National Carer Strategy Online Workshops (OW), held in August 2024. The carer insights and proposed solutions from these sessions provide a strong skeleton for the revision of the National Carer Strategy to ensure carers can continue to participate in paid employment, education and the economy; experience less red tape and bureaucracy; are recognised by the health system, in the workplace and the education system; and are able to plan for the future.

Despite the disparity between the workshops (with one session dedicated to school-aged carers and the other including a diverse range of carers), carers are experiencing similar challenges that manifest differently depending on their age and stage of their caring journey.

Carers need flexibility in the workplace and education system if they are to have same opportunities as other Australians to participate in society, the economy and to secure their own financial future; many carers commented on the social and financial costs of caring.

Carers often felt compelled to leave the workplace due to the demands of caring, and lack of workplace flexibility and recognition of their caring role. Likewise, school-aged carers can feel penalised and misunderstood, with little flexibility to balance caring, school obligations and friendships.

No matter the age or stage, carers worry about their future, ageing carers worry about succession planning and younger carers about their future when their education and social networks are being impacted by their role. Many carers also face a relentless and continuing career journey throughout their lives (caring for multiple people at the same time and/or individuals across time).

Carers identified that a 'carer identification card' might assist in being recognised by the health care system, medical professionals, service providers, within the community and in the education system. Almost universally, carers want an easier-to-navigate service system (Carers Gateway) and assistance with navigation via a 'carer concierge' model.

Addressing these challenges within the National Carers Strategy and in broader government policy will create more equity and acceptance for Australia's three million carers.

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# INTRODUCTION

Carers Australia appreciates the opportunity to provide input to the Department of Social Services (DSS) National Carer Strategy consultation. Carers Australia was engaged by DSS to assist the department by gathering data, insights and lived experience narratives through coordinated consultation with a diverse range of carers to inform the design of the 2024 National Carers Strategy.

During August, Carers Australia organised two online workshops, the first with young carers (under the age of 18) where most of the 25 attendees were still enrolled in school. The second workshop had 11 attendees which represented a diverse range of ages (including several self-identified ageing carers).

A total of 36 carer participants' views (including some speaking on behalf of/sharing experiences from advocacy groups) from metropolitan and regional locations. The report includes the views of carers who:

- are carers of people with dementia
- are carers of people with mental health illness
- are young carers under 25 years of age
- are carers for people under 25 years of age
- are carers over 65 years of age
- are providing care for more than one person (simultaneously or across their caring journey)
- are supporting primary carers by caring for others in their household, and
- are former carers.

Online workshops addressed two key aspects of carers' needs via:

1. A discussion of known challenges for carers and exploration of how participants' experience may be similar, or different to those challenges based on their demographic, caring theme (such as being a carer of someone with dementia) or location.
2. An exploration of possible solutions to the key issues identified in Part 1.

This report is arranged into thematic sections based on consultation areas that DSS requested including carers supporting people living with mental illness, dementia, veterans and other insights. Information on palliative care carers is not included in this report but has been included in Carers Australia's report on the Outreach Roundtable consultations.

Challenges and solutions are ordered by the domains affecting carers:

1. Health, safety and wellbeing of carers
2. Education and life skills for carers
3. Identification and recognition of carers
4. Balancing work, volunteering, education and care
5. Access to quality supports and navigating complex systems
6. Financial wellbeing of carers.

All focus group participants were compensated financially for their time and have provided consent for their stories, including quotes, to be used within this report.



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# IDENTIFIED ISSUES

*"What happens with him when I'm not able to look after him?" (OW 2)*

*"You may not be able to have friends because you're not going to school. You're at home. You're caring." (OW 1)*



## Health, safety and wellbeing of carers

- **Ageing carers – concerns for the future and succession planning (OW 2)**
  - Ageing carers experience additional stress and worry compared to other carers as they look to future-plan and future-proof for the person they care for (succession planning). With the realisation that the person they care for will outlive them, carers want to ensure that the person they care for has the best possible care secured for their future. A carer representing an advocacy group noted this was a primary concern among members; *"The thing that worries us most is what to do about succession when we no longer can."*

Current systems are not well equipped to assist carers with this process. It can be even more complex and stressful when a carer cannot be identified as a 'successor,' for example, they may be the last surviving parent, there are no siblings, or siblings willing to undertake the carer role.

Several carers are also concerned about housing security and safe accommodation for the person they care for.

Some carers also find themselves having to make difficult financial decisions now, in order to secure the future of the person they care for. Sometimes this has negative ramifications if they misinterpret government regulations. An example given was a woman selling her house to provide housing for her children; there was an unintended impact on her aged care pension; *"She's actually fighting with the tribunal because of pensions being taken off her. She can't even get hardship pension."*

- **Relentless and continual caring journey**
  - Several carers are experiencing a relentless and continual carer journey, which impacts their health and wellbeing, and tests their resilience over time. This means that whilst they may start caring for one person, they may then find themselves caring for multiple people within the family at the same time (with additional caring responsibilities developing over time), caring for one parent then the other parent, assuming responsibilities for a sibling as parents age, and/or assuming responsibility to care for other carers.

One carer shared their experience caring for other carers; *“Now my major support and caring role is actually for two other friends who are caring for their partners with dementia, and I'm sort of caring for them.”*

Young carers (OW 1) shared the experience of caring for multiple people within their family, sometimes having responsibilities caring directly for the person requiring care and/or caring for others in the home (often siblings) as their parent/s/carer/s need to focus on a primary family member needing care. Many young carers may also find themselves on a relentless and continual caring journey as their parent/s/carer/s age or pass away. This means young carers may be on a continual and changing carer trajectory across their lifetime.

- **Social isolation for young carers (OW 1)**

- School-aged carers identified that they have problems making friends, and experience social isolation. Several identified it was hard to make or keep friends as they miss school due to caring responsibilities. Friends may also not be comfortable coming over to the carer's house, which makes it difficult to socialise when the young carer has responsibilities at home. Friends may not always understand why they are missing school, *“and obviously when you're not at school, your friends, especially now, are gonna talk about you. And they're not gonna say good things. So you lose those friends.”*

One carer shared how social isolation can amplify the stress of caring and issues with friendship groups; *“I didn't leave the house. Self-isolation in that I didn't talk to anyone. I didn't have any friends because it stressed me out and gave me a lot of anxiety.”*

Young carers can also miss out on experiences like school camps, interstate and overseas excursions, further adding to peer group isolation (not having shared experiences), and missing important educational opportunities. *“I didn't really get to experience what it was like to go to Japan because we had a Japan trip, and I was really looking forward to that. But then my dad was in the emergency department.”*

Several young carers also shared that they are living with conditions like ADHD but are still taking on caring responsibilities. This combination can further add to the complexities of balancing schooling and establishing friendship groups.

*“So many people refuse to actually recognise that a carer is an unpaid support worker.” (OW 2)*



## Identification and recognition of carers

- **Self-recognition**

- Several carers in OW 2 reflected that it took them some time to recognise for themselves, and accept, that they are carers. They noted that once they embraced

this, it could be empowering. Sadly, carers shared that the stigma around mental ill health did create additional challenges for them.

- **Ageing carers**

- Participants in OW 2, who considered themselves ageing carers, not only worry about the future of the person they care for, but they also want *“for the government to look after ageing carers. Some of us have looked after someone for a very long time.”*

- **Recognition from medical professionals**

- A common theme across multiple consultations, OW 2 participants identified how they aren't consulted or heard by medical professionals, particularly when the person they care for has mental ill health. This was thought to be even more challenging when caring for teenagers, as often carers thought that teenagers' behaviour was dismissed by medical professionals as hormonal, and carers' input wasn't heard or valued.

This experience was shared by one carer; *“My teenage daughter was diagnosed quite young. But that's really because my husband has the same diagnosis. And so, it was clear when she started exhibiting the same symptoms when she hit her teenage years, what was going on. But we're an unusual circumstance and I had to advocate for that, because doctors are reluctant to diagnose in the teenage years because there's so much in the way of hormones going on that can affect everything. So, it was a bit challenging, a lot of me taking notes, delivering those notes to the doctor. Not taking the first 'NO', but going, 'OK, there is really something seriously wrong here.' A lot of advocacy on my part.”*

OW 2 participants also discussed how medical confidentiality can be used as a barrier to assisting the person they care for. One carer described it as having, *“the confidentiality barrier put up when what we're trying to do is just let people know about the information [when] we can actually support that person's journey.”*

- **Carer allowance**

- Carers in OW 2 felt underfunded for the work they perform. Carers note that the carer's allowance is small, especially when they have had to stop paid employment due to their carer role. Carers felt this undermined the value of their role, accompanied by having real financial impacts. One carer who also receives an aged pension said, *“the allowance that I receive as a carer, I find astronomically small.”*

- **Workplace recognition**

- OW 2 discussed several employment challenges and identified a need for better recognition, including having questions (data collection) on carers in the workplace surveys. One carer noted that as a significant employer, the State of the Service Report (APS) does not ask any specific carer questions (Carer's Australia notes that leave absences due to caring responsibilities are captured, but this also includes parenting responsibilities).

- **Carers' Acts**

- Several carers in OW 1 were aware of various Carers' Acts that exist within Australia, but also identified that these have no teeth; carers felt that *"not one of them"* made much difference because *"if you don't follow the Act, there's no penalty."* There was a view the Acts are *"just parliamentary waffle to make themselves sound really good, but there's no force, none whatsoever. They're all recommendations."*

- **School recognition**

- The education system is failing to recognise young carers or accommodate their needs to ensure they have access to the same quality education as other students. This can have compounding impacts; young carers miss out on opportunities for respite, opportunities to develop social networks at school, and long-term education and learning ramifications.

For example, the pressure of assignments and homework deadlines means young carers are finishing assignments in recess/lunch time, on the bus, or at school before school starts, just to have it done before they get home as they have no time at home for homework. This means they are not having any real break or socialisation across the school day.

Teachers often fail to recognise that caring responsibilities may be for multiple family members or may not be for the primary person needing care. Young carers often assume responsibility for other siblings or are picking up household responsibilities that aren't expected of their peers.

These dynamics are complex. *"Even if you're actually caring for one person in particular, and one person has the condition or the disability, that doesn't mean you don't have other people in your family that you have to care for. For instance, my family consists of two adults and four children. I care for one of my family members. But because one of my family members has a condition or a disability, it takes time for the other people around me as well. My two parents have to look after my sister pretty much 24/7, so that leaves me to look after some of the things that they can't do. I have to look after the other siblings."*

- **General recognition of young carers**

- Young carers are not immune to other cohorts who feel unrecognised for their contributions. *"I feel like we can get forgotten about because we're not as open if we have our own struggles. Because it kind of feels like we need to focus mainly on our siblings, our parents, whoever we need to care for, so we can get forgotten about if we need help."*

*"If you don't have a manager who supports you in your care role, you have to leave the job. You can't stay. It's impossible." (OW 2)*



## Balancing work, volunteering, education and care

- **Flexible employment**

- OW 2 focused a lot on employment issues. Several carers and former carers shared that they had to leave their paid employment to manage their role as carers. For many, this was a reluctant decision with one carer discussing the need to quit their job (teaching) to care for someone who lives with them full-time; *"I was working part-time and I've now retired because I got tired."*

There was common agreement that working full-time and caring was like managing *"two full-time jobs,"* and carers also know the 'decision' to leave work has a financial impact on them. *"I retired early, and I think I lost a lot of money in my retirement. I just couldn't do both."*

- **Leave entitlements**

- Carers want better recognition in the workplace. They want supportive employers who recognise the pressure and responsibility of caring and the need to take leave to manage caring responsibilities. A lack of flexible working arrangements has forced some carers into the decision to leave paid work. *"I asked for a flexible return to work. 'Can you hold my position, like (you do for) maternity leave? Please, hold my position for three months or six months whilst I look after my son, and (then) return to work on reduced hours.' But there's not that flexibility. I was told, 'Well, if you can't work full-time, you'll need to find another job'."*

Carers said there is not enough personal leave to cover caring responsibilities, and they also want to see separate categories for 'parenting' versus 'carers' leave. Carers who have exhausted their leave find they then have no personal leave for themselves, and often have to take unpaid leave once allocated leave is exhausted, adding further stress to their wellbeing and financial security.

*"The other issue is we get, what, around ten days a year of sick leave? But out of that comes your careers leave as well, so I would not have any sick leave leftover because it would be used for my son. Which means the rest of my leave was unpaid leave. It needs to be a separate bucket, if they're serious about carer wellbeing and flexibility."*

- **Flexible schooling**

- The young carers who took part in Online Workshop 1 identified a lack of understanding and recognition of their circumstance, and the impacts on their engagement in education.

Caring responsibilities can impact school attendance (including excursions) and the ability to meet deadlines for homework and assignments in a way not experienced by the broader school population. Young carers want, and need, more flexibility to fully participate in the education system and more understanding on why they are struggling to meet certain expectations.

Young carers shared experiences of detentions and other penalties for missing deadlines. One carer shared how they were punished by their school for missing a deadline due to caring responsibilities for a sibling; *"I went to school the next day and I was trying to explain, but they just didn't understand. Because I didn't get my assignment done, they sent me to 'reflection,' and you've got to stay in reflection all day. You don't get to be in class."*

The pressure of missing school deadlines whilst caring can have unintended and long-term impacts on a young carer's education trajectory. One carer left school and moved across to TAFE. At school, *"you get assignments on top of assignments on top of assignments; then homework. That's a big reason that I left school and went to TAFE. I'm grateful that I've got TAFE and it has made things a lot easier."*

Sadly, some teachers don't show compassion or understanding for young carers, even if they find themselves with caring needs throughout the school year.

*"After hours you're just out in the cold." (OW 2)*



## Access to quality supports and navigating complex systems

- **One approach does not fit all**
  - OW 2 carers were diverse in age, location and who they cared for. As such they highlighted there is no 'one size fits all' approach that can be rolled out by the government. As one carer described it, *"there's such a range of different types of carers, from the people who deal with parents with dementia or partners with dementia to the people who deal with children with disabilities or younger adults with mental illness problems. And they all have different needs. There's no one approach that fits all of them. They need to be approached in different ways."*
- **Succession planning**
  - Ageing carers worry about the quality of support and future care of the person they care for. Many are not confident about future service provision. *"I'm an ageing carer and I'm now focused on what happens with him when I'm not able to look after him. Where might he live? And be cared for, and looked after? That's where I'm at."*
- **Service navigation and the Carers Gateway**
  - *"I haven't heard one good word about Carers Gateway,"* summed up the majority opinion of Online Workshop participants.

Participants are frustrated with navigation, being forced to use chat bots, the high turnover of staff and inexperienced staff, referring to the system as *"universally*

*appalling.*” There was some recognition that occasionally you could be connected with an experienced APS officer who could navigate the system, and/or someone with lived experience and therefore empathy, but after several poor experiences, many carers give up using the Carers Gateway.

One carer, who is also part of a carer network/advocacy group of around 450 people, said the group identified 21 issues they want addressed in the mental health system, noting the top priority as service navigation. Whilst they recognised some issues were the responsibility of the jurisdictions, they still called for better coordination and interoperability between the Commonwealth and the jurisdictions.

A mother summarised her navigation journey as, *“My daughter was diagnosed when she was three, and it's taken me seven years to figure out the system.”*

The way cases are managed and closed also creates frustrations for carers. Workshop participants pointed out that once a case is closed, *“you need to set up another one if there are periods of no assistance required.”* This isn't helpful and is cumbersome, especially when caring for people with lifelong disabilities. It was assumed practice persists for the purpose of data collection; however, it makes carers feel like a misinterpreted number, chalked up to success whenever a case closes. *“I don't really need any help at the moment ... but then your case ends, and to get more assistance you have to start up a new case.”*

Carers identified this is not a person-centred approach and was purely outcomes focused. The rigidity of the system also adds to carer frustration.

- **When a carer needs care**

- Several carers shared their experience of either needing care and support themselves (for example through My Aged Care) or assisting another primary carer when they suddenly need care (examples included a cancer diagnosis and a broken hip for carers of people living with dementia).

The challenges identified included the primary carer now needing to navigate the system for two or more people, and the impact of long wait times for their own care on their ability to care for others.

- **Respite**

- Respite has been a consistent issue discussed across consultations. In OW 2, one carer identified that due to the complexities and changes with the respite policy, they have taken matters into their own hands, organising fundraising to support and fund carer to access respite.

- **Schools**

- Carers with school-aged children face many challenges, and some suggested that schools have a bigger role to play. One carer said that her child's school identified their child may have autism, *“but they didn't help any further, and that that was as far as they took it.”*

Parents and carers would like to see more dedicated focus on teens, and early diagnosis and intervention on mental ill health issues. One carer suggested this approach might help teens *“avoid the adult problems that I've had.”*

- **Mental ill health and homelessness**

- Carers of those living with mental ill health worry about the risk of homelessness for that person, especially when having difficulties obtaining a diagnosis, or when they cannot support them in the family home.

*“I've got the same expenses, and I'm still a carer for my son. It's just that he's not in the bedroom down the hall” (OW 2)*



## Financial wellbeing of carers

- **Cost of assessments**

- One carer said the cost of assessments, especially on a carer payment, is prohibitive. *“I can't afford the cost. I can't access assessments for myself and my son because they want \$1,700 for each assessment. I can't afford that, especially with the low income support.”*

- **Cost of caring**

- Several carers discussed the difficulty of managing finances on a carer payment (though sometimes when combined with other payments). Occasionally payments change (reduce), for example if the person being cared for moves out of the family home. The financial burden to the carer remains unchanged (or minimally changed), or can potentially increase (for example with increased travel costs associated with caring). There is no transition period or financial advice provided to support carers when they experience a change in benefits.

As noted above, many carers discussed the loss of financial security due to the need to leave paid employment to undertake their caring responsibilities.



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## Health, safety and wellbeing of carers

- **Ageing carers**
  - Ageing carers want the provision of advice on how to ensure the financial security of the person they care for after they pass (and on minimising any impact to them in the interim). What they would benefit from is *“a source of legal advice on how to manage leaving our assets in a way that that our loved ones have looked after.”*
- **Peer support for young carers**
  - Young carers want more online peer support programs and more in-person peer support programs in more schools.

*“We value what you’ve done. And let’s fast-track you on the path to qualifications.” (OW 2)*



## Identification and recognition of carers

- **Recognition of experience towards relevant qualifications**
  - Participants in Online Workshop 2 suggested that skills learnt ‘on the job’ could be taken as credit for qualifications should carers want to enter paid work in the sector. This would help them with employment opportunities, job flexibility and financial security, and provide empathetic and experienced carers to an industry in need of such experts. *“Let’s recognise the job that you’re doing, and let’s set us on a skills path. A lot of young carers have just the ethical background that you want. You don’t have to sit with people just leaving school or people that have had no experience – we value what you’ve got. We value what you’ve done.”*
- **Carer registrar/identification card**
  - Multiple cohorts of carers (those who care for veterans/ADF families, etc.) have expressed support for a specific registrar/identification card for them; however, OW 2 proposed a Government Carer Registrar. Their proposition would allow access to a national help desk, and, as such, the access to a ‘carer concierge’ (someone to help carers navigate systems and access).
- **Young carer registrar**
  - Carers suggested an enrolment process with a way to self-identify. This would then be used to manage the differing needs of young carers within the education system. This could include a personalised learning plan, flexibility with assignment deadlines and exams (especially without the need for medical certificates, which only adds to the burden young carers already face). It would also recognise that young carers may not always be acting as a primary carer, or may be caring for family members other than the party identified as the one in need of care.

*“For all the non-essential subjects, which I knew I was never going to use in my life, I turned them into study periods to catch up on the work that I would otherwise have to do at home.” (OW 1)*



## Balancing work, volunteering, education and care

- **Employment**
  - Carers want more respectful and flexible workplaces, dedicated carer leave so they do not have to exhaust their own allocation, and better data on their experiences.
- **Education**
  - Young carers proposed personalised learning plans. These could allow them access to non-assessed class time to catch up on study, homework and assignments. One carer identified this would be much more beneficial than a life skills class that teaches students how to create a schedule – young carers have been juggling personal, professional and prescriptive calendars from their first day of assuming a caring responsibility.

*“I kept the English, science and maths, and some others. But for all the non-essential subjects, like food sciences and woodwork, which I knew I was never going to use in my life, I kind of turned them into study periods to catch up on the work that I would otherwise have to do at home. I didn't have the time to do (them) at home.”*

Where school attendance requirements are mandated – for example, 90% attendance – the requirement should be lowered for young carers.

- **Distance/virtual education options**
  - Some carers would benefit from the option of distance education (remote learning) as this can provide flexibility for learning hours, coupled with the opportunity to attend/meet teachers and other students in person. A handful of schools already offer this flexibility, and the benefits can be significant. *“I can do my schoolwork outside of those normal 9-to-3 hours, or I can just pick and choose when I need to do it around appointments and helping with my sister. And I can save on travel time.”*

*“There should be resources behind the system, behind the people. To support them, to support us.” (OW 2)*



## Access to quality supports and navigating complex systems

Carers that participated in Online Workshop 2 reiterated they want *“to see the government actually delivering on the services that it advertises.”* These carers also want to have better

drafted legislation to stop the frustration carers feel about whether they can *“take them [the government] to consumer affairs on it or not.”*

- **Carer concierge**

- Extending on from the carer registrar mentioned above, OW 2 identified having a ‘carer concierge’ to assist them on their journey would be a huge improvement to resource access. One carer shared their experience of a similar model in palliative care and having a ‘consumer representative:’ *“These are people around Victoria who are there to help people navigate the system, which is what their job title is. If you had a system like that available to carers, that would get rid of a lot of these problems, because you have people who know their way around the system.”*

Carers proposed a system similar to a *“help desk, (where) you have work flows like you do in other organisations, so that you don't necessarily have to have lived experience. You just have to have some compassion and empathy.”* Users could then access a ‘fact sheet’ that would signpost them to available resources and further information, and the ability to contact a dedicated carer concierge.

Participants acknowledged, *“Services Australia is not customer service orientated,”* so a new approach is required.

Other carers identified proactive check-in calls from the Carers Gateway would be beneficial. The example of support when navigating palliative care provided a possible way forward: *“They rang regularly. It got to weekly, sometimes every second day, and they would ring and check (on me). That was very reassuring.”*

- **Alternative delivery models**

- One carer in OW 1 proposed that a more people-centred approach to service delivery could be via local libraries. *“Libraries could be an amazing resource.”* And with libraries in most urban and regional communities, and some in remote communities, the proposition of a centralised hub of information is worth exploration.

- **Teacher training**

- Teacher training should include young carer education – educators should understand what a young carer is, how their caring role may impact them at school and outside of school, and how they might adjust for and support their student carer.

When teachers and schools recognise and make adjustments to personalise education for a young carer, it can have significant impacts. *“Towards high school I became an advocate for young carers, and my school recognised me individually because of that role. They made adjustments, like having more effective online resources and the ability to put lessons online while I was away. And I picked up from failing in school to being able to achieve my education. It's possible for them to make changes!”*



## Financial wellbeing of carers

- **Young Carer Bursary**
  - The Young Carer Bursary has positive impacts and outcomes for carers. *"I definitely like the bursaries. They've helped my family a lot. And the funding they give for (a) laptop (and) school supplies helps so much."*

# BACKGROUND

For the purposes of this submission, the term 'carer' is defined as per the meaning under the [Carer Recognition Act 2010 \(Cth\)](#)<sup>3</sup>: that a carer is an individual who provides personal care, support and assistance to another individual who is living with a disability, medical condition (including a terminal or chronic illness), mental illness, or who is frail and aged. Carers Australia also recognises carers supporting those living with addition. 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.

## CARER SNAPSHOT

There are three million carers in Australia, with approximately two thirds caring for someone under the age of 65<sup>4</sup>. Two thirds of primary carers are women<sup>5</sup>, 30% of carers are from multicultural backgrounds, and 14% of the Aboriginal and Torres Strait Islander population are carers<sup>6</sup>.

In 2022, 38.6% of primary carers also identified as living with a disability<sup>7</sup>. Being a carer is a constrained choice and a significant commitment that impacts many aspects of a carer's life. Results from the Caring for others and yourself: 2022 Carer Wellbeing Survey (Survey), identified approximately 30% of primary carers are providing more than 40 hours of care per week<sup>8</sup>.

The survey identified that compared to other Australians, carers are 2.5 times more likely to have low wellbeing, twice as likely to experience psychological distress, are 2.8 times less likely to have good/excellent health outcomes and are 1.7 times more likely to experience significant financial.

The annual economic value provided by carers has been valued by Deloitte Access Economics at \$77.9 billion per year<sup>9</sup>.

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<sup>3</sup> Carer Recognition Act 2010 (Cth)

<sup>4</sup> Australian Bureau of Statistics, Survey of Disability, Ageing and Carers (SDAC) 2022

<sup>5</sup> Australian Bureau of Statistics, Survey of Disability, Ageing and Carers (SDAC) 2018

<sup>6</sup> Australian Bureau of Statistics, Survey of Disability, Ageing and Carers (SDAC) 2022

<sup>7</sup> Australian Bureau of Statistics, 2021

<sup>8</sup> Carers Australia, Caring for others and yourself – Carer Wellbeing Survey 2022

<sup>9</sup> Deloitte Access Economics (2020), The value of informal care

# APPENDIX 1

## PARTICIPANT PRE-SURVEY DATA

Please note that completing the pre-survey was optional, and not all carers participating in focus groups chose to complete the survey.

#	AGE	STATE	LOCATION DENSITY	AGE BECAME CARER	LIVE W/ WHO YOU CARE FOR	HRS/WK CARING	EMPLOYMENT STATUS	WHO DO YOU CARE FOR AND WHY DO YOU PROVIDE CARE
1	18	VIC	Metro	15	Yes	20-49 hours per week	Not currently employed	Mother with chronic illness
2	14	VIC	Metro	6	Yes	0-19 hours per week	Not currently employed	Younger brother (mental health and disability) Mum (mental health, disability and chronic health)
3	20	VIC	Metro	16	Yes	20-49 hours per week	Not currently employed	Mother (mental health and chronic illness)
4	16	WA	Regional	6	Yes	50+ hours per week	Not currently employed	10yo sister (complex medical needs, physical and intellectual disabilities)
5	16	ACT	Metro	13	Yes	0-19 hours per week	Casual	18yo sister (autism, FND which has left her non-verbal and unable to move anything but her hands)
6	15	NSW	Regional	10	Yes	0-19 hours per week	Casual	Sister (disability)
7	15	WA	Metro	13	Yes	0-19 hours per week	Not currently employed	Father (mid-stage Parkinson's)
8	16	QLD	Metro	6	It's complicated	0-19 hours per week	Casual	Brother (17yo, ASD, ADHD, ODD) Sister (13yo microcephaly) Brother (6yo, ADHD)

#	AGE	STATE	LOCATION DENSITY	AGE BECAME CARER	LIVE W/ WHO YOU CARE FOR	HRS/WK CARING	EMPLOYMENT STATUS	WHO DO YOU CARE FOR AND WHY DO YOU PROVIDE CARE
9	14	NSW	Regional	9	Yes	0-19 hours per week	Not currently employed	Sister (disability)
10	17	VIC	Regional	12	Yes	20-49 hours per week	Not currently employed	Mum (chronic pain, vision) Sister
11	16	VIC	Metro	12	Yes	0-19 hours per week	Not currently employed	Mum (mental illness)
12	16	VIC	Metro	12	Yes	0-19 hours per week	Not currently employed	Mum (mental illness)
13	14	SA	Metro	10	Yes	0-19 hours per week	Casual	Brother (disability)
14	17	VIC	Metro	13	Yes	20-49 hours per week	Not currently employed	Disability
15	16	VIC	Regional	11	Yes	20-49 hours per week	Not currently employed	Mum (vision, neurological condition)
16	15	SA	Metro	7	No	0-19 hours per week	Not currently employed	Father (dementia, ABI)
17	18	VIC	Metro		It's complicated	0-19 hours per week	Casual	Mother (disability)
18	18	VIC	Metro	15	Yes	20-49 hours per week	Not currently employed	Mother (chronic illness)
19	15	SA	Regional	11	Yes	50+ hours per week	Not currently employed	Father (chronic debilitating neurological condition)
20	16	NSW	Metro	10	Yes	50+ hours per week	Not currently employed	Five brothers (four are autistic, two have ADHD, and two have epilepsy)
21	15	VIC	Regional	13	Yes	0-19 hours per week	Not currently employed	Father (seizures, medical conditions)
22	14	VIC	Metro	13	Yes	0-19 hours per week	Not currently employed	Father (chronic illness, disability)

#	AGE	STATE	LOCATION DENSITY	AGE BECAME CARER	LIVE W/ WHO YOU CARE FOR	HRS/WK CARING	EMPLOYMENT STATUS	WHO DO YOU CARE FOR AND WHY DO YOU PROVIDE CARE
23	15	VIC	Metro	12	Yes	50+ hours per week	Not currently employed	Mother (mental health and carpal tunnel syndrome)
24	15	VIC	Metro	14	Yes	0-19 hours per week	Not currently employed	Mother (mental health)
25	75	NSW	Regional	30	No	0-19 hours per week	Casual	Father (now deceased) Mother (92yo, in nursing home, anxiety)
26	71	VIC	Regional	59	Yes	50+ hours per week	Not currently employed	Adult son (mental illness)
27	18	VIC	Regional	17	Yes	0-19 hours per week	Casual	Father (chronic illness)
28	75	VIC	Metro	45	No	0-19 hours per week	Casual	Adult son (schizophrenia)
29	73	VIC	Metro	61	Yes	50+ hours per week	Not currently employed	Late wife (pancreatic cancer)
30	49	NSW	Metro	17	Yes	20-49 hours per week	Full time	Partner and two children (disability)
31	36	NSW	Regional	20	No	0-19 hours per week	Part time	Father (schizophrenia, bi-polar and severe depression)
32	43	NSW	Regional	29	Yes	50+ hours per week	Not currently employed	Son and daughter (mental health, disability)
33	57	NSW	Regional	38	No	0-19 hours per week	Casual	Son (mental health, neurological disorders, chronic illness)



## ABOUT US

Carers Australia is the national peak body representing the diversity of the 3 million Australians who provide unpaid care and support to family members and friends with a disability, chronic condition, mental illness or disorder, alcohol or other drug related condition, 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 represent 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.

For further information on this report, please contact [policy@carersaustralia.com.au](mailto:policy@carersaustralia.com.au)