



# **NATIONAL CARER STRATEGY CONSULTATION: FOCUS GROUP INTERVIEWS**

Prepared for the Australian Government  
Department of Social Services  
July/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

*“There’s no training for being a carer. There’s no training at school, there’s no training in university, there’s no training in life. Unless you know a carer, you have no training whatsoever.”*

(Focus Group 16)

Removing barriers, and respecting and caring for the carer, are key to their empowerment and wellbeing. Continual improvement of the ecosystem in which they operate is essential.

Carers best understand what they need and the shortfalls in what they are currently being provided. Carer insights need to drive the revision of the National Carer Strategy to ensure carer wellbeing is maintained and sustained, to demonstrate they are valued and recognised, to remove barriers and to support carers in supporting those they care for, and to ensure that any financial impacts incurred as a carer are minimised.

A total of 257 carers took time out from their caring and other commitments to provide invaluable insights and solutions on carer issues. Participants included young through to mature carers living in regional/remote and metropolitan areas providing care to a broad spectrum of people, with some caring for multiple people.

Despite the range of caring relationships, several common themes emerged; carers need genuinely flexible respite no matter where they live (including emergency respite); carers want to be recognised and receive informal support from their family, friends and the community; and carers want the same rights and opportunities to participate in the workforce and attain an education as other Australians. Carers also identified shortfalls in formal government and health supports, including a lack of education to assist in their care journey, and issues with the interoperability and transparency of government support services such as the National Disability Insurance Scheme, My Aged Care and Centrelink. Carers also identified the need for health, wellbeing, community and financial support once their caring responsibilities end.

Some carer cohorts experience issues more severely than others and have additional unique challenges. This includes carers living in regional and remote areas with less available services, and greater costs associated with travel; young carers trying to navigate and balance the school system, work, socialising and care; and Australian Defence Force families managing their lives within posting cycles involving regular moves across jurisdictions and internationally.

Caring is a constrained choice, and carers frequently put themselves second to those they care for, at times sacrificing their basic Human Rights (UDHR) including the rights to rest and leisure and to participate in the cultural life of the community. We owe it to Australia’s three million carers to develop a strong, considered and supported National Carers Strategy.

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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 July and August, Carers Australia organised 23 focus groups with a diverse range of carers, across Australia recruited to participate in these focus groups.

Delivery of each focus group, including recruitment of carers, logistics, support, facilitation and notetaking were delivered by the National Carer Network and Dementia Australia. Peer, peak, carer organisations including Partners of Veterans, GLBTI Rights in Ageing Inc. (GRAI), Mental Health Carers Australia and Eating Disorders Families Australia supported recruitment of a diverse range of carer participants and provision of additional insights. A total of 257 carer participants' views are reflected in this report, including the views of carers who:

- are carers of veterans
- are Australian Defence Force family with caring responsibilities
- are carers of people with dementia including younger onset dementia
- are carers of people with mental health illness
- are young carers under 25 years of age
- are carers in regional, rural and remote geographies
- are carers over 65 years of age
- are caring for people who identify as First Nations people
- are former carers.

Focus groups 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.

# CARING FOR SOMEONE WITH A MENTAL ILLNESS



# IDENTIFIED ISSUES

*“My bucket is so bloody full, it’s overflowing. You get to the end of the day and what it takes not to sit there and burst into tears because you’re just grateful that you’ve got them to the end of the day, you’re not worried about yourself.” (FG 10)*



## Health, safety and wellbeing of carers

- **Impacts on carer mental health**
  - Focus group participants ranked the impacts of being a mental health carer on a carer’s own mental health as a top issue.
- **Respite**
  - Participants also discussed respite being absolutely necessary for recovery, and described it being a right, not a privilege.
- **Respite used for tasks**
  - Whilst respite is needed for carers to take a break, this is rarely the case. Given gaining respite is so difficult, carers often use it to do a task they need to do rather than take any time out. One participant summarised this situation well, *“If you ask for respite, just, no, there isn’t any”* (FG 10).



## Identification and recognition of carers

- **Societal recognition**
  - Carers feel unrecognised, unseen and ignored, describing their situation as *“almost underground”* (FG 7).
- **Recognition from health professionals**
  - Carers describe interactions with medical professionals, health professionals and departments as transactional; *“They don’t see the person – they don’t even look. They don’t actually physically see the person anymore”* (FG 10).

Carers feel ‘fobbed off’ during meetings and feel that they are not taken seriously by health professionals, that their expertise isn’t recognised, and are frustrated with the lack of follow through post meetings. Adding to this frustration is that carers invest a lot of time and resources into attending these meetings.

Carers also reported they are not provided with information to assist them in their caring role or referred to support groups or other carer supports.

As one carer lamented, *"I'm still learning every day about my husband's depression and triggers and things like that and how I can help him in his time of need. What can I say for him? I don't know what to say when he's having that depressive state, what can I say to help him? There's been no information given to me about his condition, there's been no support groups to sort of help me understand that I've jumped into this, we've been married nearly 12 years and I'm still learning to this day what I can actually say and do"* (FG 4).



## Balancing work, volunteering, education and care

Carers described that capacity not capability was the major challenge to balancing work, education, volunteering and care. Some described working very early hours so they could get 'some social time in' before returning to their caring duties.

- **Paid employment**

- Several things can impact opportunities for mental health carers to engage in paid employment:
  - the 'unpredictability' of mental health caring can impact the ability to remain in paid employment
  - wait time for care packages, gaps in support between packages and review times. For example, if a NDIS plan finishes and the wait time for the next review is six months, this interrupts the carer's employment opportunities while they take time out of the workforce to provide additional care in-between packages.

Caring responsibilities can make it impossible to remain in certain career vocations. An example provided was a chef who could only work 6:30am to 10:30am to be able to cover caring responsibilities, and so was working as a cleaner instead of a chef.

A carer noted that, *"I used to work full-time and then I worked part-time because it was all too hard looking after him. Trying to work and do everything else. And I eventually retired because it was, I just couldn't deal with the whole thing with looking after him. And I'm a sole carer"* (FG 7).

- **Study**

- Even with advanced planning, carers often faced barriers to studying. *"I had enrolled in university because we have aged care coming to the house, except they were not turning up. So then I couldn't, and couldn't do my lessons online"* (FG 10).



## Access to quality supports and navigating complex systems

- **Carer support services are limited**

- Many participants have described how they have to train support workers which adds to the carers 'workload'. This included how to care, how to follow a care plan

and even what a care plan is. Training may be needed due to particular needs of the person they care for, because the support workers didn't follow the care plan, or because the support worker doesn't have any training at all.

*"I seem to be training staff that are coming out to care. Okay, there's a level expected, there are Certificate III's (training qualification), I thought that it had to be a thing, but very few of them have it"* (FG 10).

One carer was able to arrange a formal care worker to cover for her when she was unwell, but as child minding was not in their position description, the carer still had to care for their other child. In this sense, the support service couldn't adapt.

- **Respite not available to regional and remote carers**
  - Mental health carers in regional areas said that respite services were not accessible and almost non-existent, this can leave carers with no respite and impacting their wellbeing. This can be extremely trying, as one carer said, *"the only respite I've had in 17 years has been two medical issues that I had when I was hospitalised, and that was emergency"* (FG 10).
- **Short secondments of health professionals in regional and remote areas**
  - Medical staff may only have a 12-month placement, resulting in staff being unfamiliar or unhelpful with what supports and services are available locally.
- **Digital connectivity in regional and remote areas**
  - Carers described being outside a regional area by as little as a 10-minute drive and not having any access to the internet (for example, near Mt Gambier in South Australia). This makes digital navigation impossible.
- **Service navigation is difficult and takes time**
  - Carers are already time poor due to juggling work, education, life and caring. Carers cited putting off administrative tasks when they simply didn't have the mental bandwidth for the inevitable frustrations and setbacks.

Waiting on the phone for hours for advice from government departments only to get differing advice or disconnected, is very frustrating and adds to carers' cognitive load. Differing advice (between departments or from within the same department) adds to confusion about already complex systems and what carers can and cannot access. There was also discussion on not being allowed to 'double dip' on financial supports but each isn't enough to pay for the needs of the person they're caring for.

Mental health carer focus group participants ranked navigating complex systems as their top issue.

- **Lack of recognition of rare conditions**
  - Rare conditions aren't recognised by Centrelink and that means carers of people with rare condition have additional trouble being recognised as carers and accessing carer allowances or payments. The example provided was selective mutism and Centrelink advised that the person suffering selective mutism 'wasn't disabled

enough'. Carers felt illness and disability shouldn't be scaled – you're either living with a disability or not.

Further, service providers often don't recognise mental illness or conditions; they focus predominantly on physical conditions. There seems to be a bias towards treating physical conditions over psychosocial ones, negatively affecting the support that mental health carers can achieve.

- **Grieving during and after caring**
  - Carers described the grieving process as a carer; grief for what could have been. They described no supports to help them with this grief.



## Financial wellbeing of carers

- **Financial distress**
  - Mental health carers bear the burden of costs for expensive assessments; with up-front fees of around \$500 for an assessment discussed. The assessment is required to enable access to supports and services but carers need to pay up-front costs even where some of the cost may be reimbursed by Medicare at a later date.

The financial impact of caring is significant both in the present and for the carer's future. One carer shared their concerns: *"It was 2012 when I was last able to work. I had a significant amount of time out of the workforce ... my superannuation now has 10 years' worth of nothing in it. So, I'm going to be an old lady living in a caravan because that's basically where I'm headed. I am not going to have a choice. I'll never be able to afford to own my own home now. I'll never be able to afford rent on my own"* (FG 10).

- **Regional and remote carers**
  - Geographically isolated carers can incur additional and expensive transport costs. Travelling to specialists (e.g. particular paediatrician or psychiatrist for assessments) can involve hours of driving and costs associated with petrol (that some carers described as unaffordable) and wear and tear, and public transport is not always available or a viable option. One carer described hiring a car, and then their doctor's appointment was delayed by three hours; the rental costs went up to \$2,000 (from the patient assistant transport that is part of a care package).

Carers noted that their carer's allowance is already exhausted on other costs like prescriptions, so travel expenses become another out-of-pocket expense.

- **Concern about making the right financial choices**
  - Mental health carers discussed a fear of not choosing the right benefit or package and inadvertently undermining support choices for the person they care for. Choosing between complex systems means they're struggling to understand the choices and benefits of different options and feel guilty that maybe they're getting it wrong on behalf of the person they care for.

# IDENTIFIED SOLUTIONS



## Health, safety and wellbeing of carers

- **Carer Connect Groups**
  - Carers rated Carers Connect Groups highly and valued peer support. They were sharing details in the focus group to encourage others to participate. Positive support services need to be promoted to carers so that it is not just word of mouth.



## Identification and recognition of carers

- **Support and recognition**
  - Whilst no direct solutions were presented, educating health professionals that the carer also requires care, support, education and referral to services may assist in addressing some of the issues identified above.



## Balancing work, volunteering, education and care

- **Opportunity to participate in paid work**
  - Carers expressed that returning to work or being able to maintain work had huge positive impacts on their mental health. Whilst no direct solutions were identified, many issues present solutions to be considered; better management of time gaps between plans for recipients, better service delivery – providers need to have workforce contingency to ensure all 'shifts' are attended (failure to attend means carers miss work or education obligations).
- **Flexibility in the workplace**
  - Carers want flexibility in the workplace, particularly for leave so that working carers can be more engaged in caring and can better manage work life balance. Examples given were carers who have a partner whose workplace do not offer flexibility, therefore they have restricted opportunity to assist with caring responsibilities.



## Access to quality supports and navigating complex systems

- **Telehealth**
  - Positive comments were made about the move to telehealth services since the Covid pandemic. Mental health carers cited better access to psychiatrists and psychologists as a result with reduced waiting lists. However, improvements are needed for access to autism assessments for regional and remote families. The wait lists for this type of assessment were cited as being 'really long', which meant carers had to wait for a very long time to get support.

- **Carer concierge**
  - A 'navigator' style support was proposed to help carers know how to access supports and what's available to them. Some carers even proposed a 'carer concierge' that help carers navigate support package applications, guidance through processes, reminders of funding renewals and reapplications and so on; a 'translator' between systems. Unlike an NDIS plan where carers don't get a coordinator until they have a plan in place, these 'navigators' can help carers get to that point.
- **Support materials**
  - Carers also proposed a directory of local services so they could find professionals like psychiatrists more easily in rural and regional locations. This would also be beneficial in metropolitan areas.

The carer journey often starts with a doctor's diagnosis, for example a paediatrician; this would be a great time to refer the carer to services or directories where they can find more information and support. Carers asked for regional, localised information not just direction for the nearest city.

A carer also suggested an information pack on diagnosis so the carer can understand what it means, *"I think that an information pack should be developed for whatever it is, whether it's autism, or it's dementia, or schizophrenia, whatever it might be. There needs to be a comprehensive pack available"* (FG 7).

To overcome doctors on short placements who didn't have local knowledge of services and supports, a booklet or similar resource was suggested.

*"So today there's so many more resources, understanding of mental illness that if we knew about at that time, she wouldn't be anywhere near as sick as she's now. And we wouldn't be anywhere near as sad and worn out"* (FG 9).

Carers suggested better advertising for service providers, perhaps even television advertisements.



## Financial wellbeing of carers

- **Financial support**
  - Carers asked that financial supports be greater – they felt current payment amounts were 'tokenistic'.

# CARING FOR SOMEONE WITH DEMENTIA



# IDENTIFIED ISSUES

*"At times I felt like dementia was tantamount to having COVID 19, where people stayed away." (FG 12)*

*"Just when you feel like you've got a routine, something else changes. There's another decline, there's another loss of independence in some aspect of my mum's life. And then you adapt to that, but then something else happens." (FG 16)*



## Health, safety and wellbeing of carers

- **Impacts on carer physical and mental health**

- Dementia carers reflected that the impact on personal health and wellbeing is significant, particularly with the hypervigilance that comes with caring for a person living with dementia. Nearly all carers spoke about the stress that manifests itself either physically or mentally. The degenerative nature of the disease is exhausting.

It was reported that sleeping is commonly impacted when caring for someone living with dementia and this has flow-on affects to other health and wellbeing issues.

One carer captured this sentiment well: *"It is constant caring. There is no letup, 24/7. You're under pressure, hypervigilant. I became one little stress ball"* (FG 15). Many carers feel there is no relief to their caring role: *"We burn out because we simply cannot get the relief we need when we need it"* (FG 15).

- **Impacts on former carers**

- A decline in mental and physical health did not only impact current carers but also former carers of people living with dementia. One carer shared her experience: *"Within a week of my husband dying, I ended up in hospital quite ill and was in there for quite a number of weeks. So that will tell you the impact that that caring role had on me"* (FG 22).

Former carers identified a long recovery journey for their own physical and mental health: *"Within a week of my husband dying, I ended up in hospital quite ill and was in there for quite a number of weeks. So that will tell you the impact that that caring role had on me"* (FG 22).

- **Family relationships strain**

- Family relationships can be strained when managing someone living with dementia, as shared by one interviewee: *"I have a girlfriend whose mother has dementia and she actually wishes she didn't have five siblings because it causes so much drama"* (FG 18). Difficulties can arise in agreeing on how to respect the person's wishes (for example not to move into residential care), denial of the condition or varying views on care management.

Changing behaviours of the person living with dementia and the strain of the caring role can also impact family relationships. Some family members find the person with dementia difficult to be around. Often there is also an assumption that family will be willing and able to assist the carer but this is not always the case, often due to discomfort in managing the person with dementia.

One carer shared the impact on her family and herself: *"My caring role has really impacted my relationship to my children and it's now imploding on the time I spend with my children because of my husband's behaviour. Not that he's aggressive, but he gets anxious and he wants to be on the move all the time. So, I can't spend the time I want with my children with him. And they work during the week, so the only time to see them is of a weekend"* (FG 18).

- **Friends and social networks**

- The strain on maintaining friendships results in social and community isolation. Carers of people with dementia often experience severe isolation and a loss of social connections due to their caring responsibilities and the stigmatisation and lack of understanding of conditions like dementia within their social circles.

This can lead to a reduction in the carers social network and informal support networks. People can drift away: *"My relationships, my social connections all fell away. Nobody wants to talk about dementia. Nobody understands"* (FG 19).

- **Lack of support for LGBTQIA+ carers**

- Carers are often be taken by surprise at the lack for support from their friends and community. A situation described by one carer was *"My experience was perhaps different from many others here in that my partner and I were lesbians. We didn't have any family support whatsoever. And where we had expected that our community would support us as happened during the HIV-AIDS years, for example; that didn't happen"* (FG 23).

*"My relationships, my social connections all fell away. Nobody wants to talk about dementia. Nobody understands"* (FG 19).

- **The person living with dementia**

- The relationship between the person living with dementia and carer can also become strained. The frustrations and sometimes paranoia experienced by someone living with dementia can have a huge unintended impact on the person who cares for them. How this can manifest was shared by a dementia carer: *"He has these little thoughts, and you don't know, it could be when he's sleeping. But I always know because he immediately goes into paranoia. He thinks I could be pregnant by someone else or I'm definitely having affairs and at that time he won't take meds, food or drink from me because he doesn't trust me. So, I find it's increasingly distressing for me because it's one thing to have your partner lose his intellect and it's another one thinking that he's thinking that you are doing things that you're not. So, on the weekend, for the first time, I had to really ask myself how long can I keep going?"* (FG 2).

The change in the relationship dynamic also impacts the carer: *"I grieve the equal relationship I used to have with my husband, the partnership I had, and moving into that carer patient role. I do struggle with that. I lay awake at night and feel really sad about that"* (FG 16).

- **Social isolation**

- The strain of maintaining relationships results in social and community isolation. Carers of people with dementia often experience severe isolation and a loss of social connections as a result of their caring responsibilities. This isolation can be compounded by the stigmatisation and lack of understanding of conditions like dementia within their social circles.

Carers of people with dementia reflected that as the person's they are caring for condition declined, so did the contact with others. In particular, physical needs, such as incontinence and increased supervision limited the carers' ability to take them on social outings. Sadly, a carer observed, *"and then as you're caring for an aged person, I care for my husband. Where are his friends now? They're long gone. Where are my friends now? They're long gone enjoying their lives"* (FG 4).

Longer times away from the home environment, such as holidays, become increasingly harder to arrange and coordination of respite becomes increasingly difficult with carers finding they become dependent on other willing family and friends to ensure that safety and care is maintained in their absence.

A husband reflected, *"Many of my personal circle of friends were indifferent to my plight of caring for my wife. Did not probe or inquire what the trajectory of caring and coping was like for me. For me the carer, this picture increased my sense of social isolation, aloneness, particularly as my wife's emerging condition was a progressive non fluent aphasia, which meant that she could no longer engage in conversations with me. Rarely did any of my friends phone me, something I'd longed for - normal conversations. Additionally, I was constrained by her condition of incontinence and cognitive impairment from visiting friends"* (FG 12).

Another carer sadly echoed this experience: *"I lost every single person, including my siblings. It affected me a lot. I went through depression"* (FG 22).

This isolation can continue even when the carer has ceased caring (for example, the person living with dementia passes away): *"I think a lot of friends and remote family have found it hard to reconnect because they were just used to you being unavailable as a carer and then just fell out of contact with you"* (FG 22).

- **Loss of identity and purpose**

- Many carers identified a loss of sense of self and social self-worth when the caring role took over their entire lives. Carers found themselves struggling with both the changing 'lost' relationship with the person living with dementia and the loss of other parts of their life that gave them a sense of self-worth as their caring role took up a greater proportion of their time. A carer grieved, *"I am no longer who I was. That is the biggest emotional loss along with the lost relationship"* (FG 14). And another reflected on their sudden change in roles; *"I was interacting internationally and then all of a sudden the next role you're in is changing continence product"* (FG 19).

Again, these feelings of identity loss can continue post the end of the caring journey: *“I think finding your identity again as to what you do and how you do it, and not realising how much caring actually took up in your life, and then finding that there was such a huge vacancy or vacuum left behind when you stepped out of those carer issues. Sudden lack of busy-ness, a vacuum of time that needs to be filled”* (FG 22).

- **Difficulty in taking the person being cared for out into the community**

- Carers want to take the person they cared for out into the community but can be deterred by public reaction to the poor cognition of the person living with dementia. Carers felt they could not just keep on apologising and constantly explaining that the person they were with had dementia.

*“I’ve often found when I’ve taken Mum out into public, and I’m wanting her to be involved as much as possible as long as possible, there’s no appropriate way of telling other people without going: ‘She’s got dementia’. She might say ‘oh, I want a muffin’ and she’s pointing to a sandwich and then we start getting into a debate with a staff member who is just not aware at all that there’s a cognitive issue going on”* (FG 2).

- **Behaviour management and safety**

- Dementia carers noted that the person with dementia’s behaviour can be physically or verbally aggressive. This could impact the carer’s safety or that of a support worker and sometimes resulted in the loss of professional care, and adding more responsibility to the carer.

This situation is very challenging for dementia carers: *“I look mainly full-time after my husband. He has multiple sclerosis and lately also he has very rapid decline in cognitive beginning of dementia. We tried a couple drugs for him now the second one to work. Because of that we lost some support worker because he started to be kind of aggressive with a few things. So I had to find other people that can understand what’s happening with him. So that was very challenging over the last few months for me, I thought that I can learn something”* (FG 9).



## Education and life skills for carers

- **Post-diagnosis education**

- Many carers complained about the length of time taken to get a diagnosis and the lack of information provided with a diagnosis, including what to expect in their particular case, how to provide care and lack of referral to dementia services. The carer has to go out and seek information by themselves and work it out.

This experience is unfortunately common among dementia carers, with several sharing similar experiences. One carer summarised it as *“actually, they just say, oh he’s got dementia. And there you go, off you go, that’s it. What’s next? What’s next? Where do you go?”* (FG 3).



## Access to quality supports and navigating complex systems

- **Navigation of complex administration**

- A dominant theme through the dementia carer focus groups was the navigation of the health and aged care systems. Carers are dealing with complex administrative and financial matters as well as caring. These can include health system access, getting access to income support, dealing with complex systems such as My Aged Care or the NDIS (where the person with dementia is under 65), setting up Guardianships or Powers of Attorney, and dealing with the financial affairs of the person being cared for. Carers find there is no 'shop front' to source the information they need and this adds further pressure to their caring role.

As one carer identified, *"there's a lot of people out there. What, over a million carers or something? How many of them know where to go and get help or guides or direction? And one big problem at the present time, is the fact of knowing where to go and where to seek assistance. I'm not going to sit on the phone for three calls an hour wait for the things to be answered, and hope to get a question answered accordingly. Like with everything in this space, who do you go to or who is available to help guide you now?"* (FG 12).

It was noted that bureaucratic processes are not designed with dementia in mind. The loss of cognitive capacity results in the administrative burden falling upon the carer.

- **Inadequacy of carer support**

- The existing support systems for carers are often inadequate, leaving them to manage overwhelming responsibilities with minimal assistance. The lack of sufficient counselling, respite care, and practical support were mentioned by many carers. *"The system is currently not providing the support needed to sustain carers. Mental health support is extremely important for dementia carers, I found that I was only entitled to six counselling sessions ... The funding given to the Carer Gateway is very restrictive"* (FG 19).

- **Respite**

- Despite high demand, there is a lack of access to emergency respite, for dementia carers, this issue was raised again and again. The need for emergency respite is critical and difficulties with access can have a significant impact on carers. Emergency respite can be required if the carer is sick or is at 'breaking point' in their caring role. *"We're supposed to have short term emergency respite. One of our carers was struggling at one time and couldn't pick up the phone and just say, 'I need help for the weekend. I can't do this anymore'. So that needs to be addressed. People become desperate in these situations. Sometimes if the dementia is aggressive they need immediate attention, not next week, and they can't book respite in two weeks or a month in advance"* (FG 2).

- **Support for carers in regional and remote areas**

- Carers in regional and remote areas noted that if they cannot travel to major metropolitan areas, they have to wait a longer period than their city counterparts to have services visit their area. *"It's very hard to get help here"* (FG 10).

*“The biggest problem is to make contact with the government agencies or whoever may be concerned are usually based in Adelaide and you have to wait until they do a run out this way...it could be next month, it could be two months” (FG 20).*

- **Early onset dementia support**

- It was discussed that there are no supports for carers of those with early onset dementia in rural Australia, not even support groups. In general carers also recognised there was very little understanding of early onset dementia more broadly, *“younger onset dementia doesn't really exist” (FG 10)*. This had the potential to impact the level of caring required and impacts on employment and engagement for the person diagnosed.



## Financial wellbeing of carers

- **Impacts of loss of employment**

- Working full-time and caring for someone with dementia is incredibly difficult with many carers moving to part-time employment, leaving work or retiring early. One carer gave up nursing to care for their dad. *“I was a registered nurse, it was hard to do shift work and look after dad, and I gave that up to care for dad, and I found the financial thing the hardest” (FG 3).*

There can be financial and wellbeing costs to changing employment. Many carers and families discussed exhausting their superannuation. *“We don't have any more super, it's all gone. We struggle from fortnight to fortnight, but we're lucky we own our own house” (FG 16)*. Others reflected on loss of career opportunities and career satisfaction. *“It's not just the money, it's all the things that you get from working. It's the social contact with other people. It's the sense of purpose, a sense of achievement, which I have to some degree as a carer, but not what work gives you for sure” (FG 20).*

## IDENTIFIED SOLUTIONS



## Health, safety and wellbeing of carers

- **Improving wider family relationships**

- Carers placed value on family mediation to help the wider family to understand the condition of the person being cared for and its manifestation: to understand the role of the carer, and to lessen the isolation of the carer when family relationships were strained. One dementia carer summarised this nicely: *“There is a need to extend access to family mediations which should include extended family members and friends so they get to know what this disease is and accept it” (FG 2).*

- **Social recognition of carers**

- Carers want society to recognise their contribution and noted that carers themselves need to value the contribution they make to the economy and to those they care for.

A number of focus groups identified the need for a national campaign directed at carers of people with dementia. This would be inclusive of social education to better understand and relate to people with dementia. Carers want more visibility. *“We need to be a bit more visible on TV advertising or social media. Any form that will attract and educate the public”* (FG 2).

- **Community education on dementia**

- The general public, including service providers (bus drivers, café staff, etc.) often do not know how to interact or range with someone living with dementia, often leaving their carer feeling obligated to explain or manage the interaction. Carers want better education of the general public so that they can support community activities with the person living with dementia without the additional pressure of ‘justifying’ that person’s behaviour. Suggestions included a dedicated lanyard or card.

*“How can I do it in a subtle way? We’ve got all these flowers, particular colours with the lanyards and stuff. There should be something for dementia where we can subtly be able to let other people know – okay, just be aware that there’s some cognitive things going on and be more understanding and empathetic”* (FG2).

*“My dad has Alzheimer’s and Alzheimer’s WA actually gave us a little card that says that this person has Alzheimer’s disease. So I actually give that out to the waiter or waitresses before we place an order and or when we go to get his eyes checked or wherever. And they kind of go, ‘oh, okay’ and they’ll be a bit more sensitive in the way we handle the patient. I just thought that was quite a clever thing and they should have this for everyone”* (FG 2).



## Education and life skills for carers

- **Post-diagnosis support**

- Dementia carers felt medical professionals (especially GPs) had a responsibility to recognise the impact of a dementia diagnosis on carers and to provide information on the diagnosis and referral to specialist dementia services.

Whilst some carers were aware of organisations like Dementia Australia and Services Australia, carers want to see this information provided at time of diagnosis. Carers also said they value their individual connection with, and advice from, their health professionals, therefore GPs need to be able to education in providing more detailed dementia information to patients and their carers.



## Access to quality supports and navigating complex systems

- **Navigation of complex administration**

- Carers of people with dementia, as with carers in other categories, placed a very high priority on the being able to access navigator support across multiple systems. These included My Aged Care, carer support services, healthcare, financial support and legal requirements.

Interconnected with system navigation is access to respite. *“If I had those two things sorted (respite and a navigation support person), I reckon it would be pretty much a walk in the park”* (FG 15).

- **Recognition from medical professionals**

- Dementia carers identified that their own expertise in relation to the person being cared for was often ignored or not sought by medical professionals. It was identified that health records should include carer insights and the medical professionals should be educated on this.

- **Respite**

- Dementia carers provided extensive solutions on respite care with respite carer being one of the great concerns for this cohort.

- **Emergency respite**

- Access to emergency respite is a significant concern, dementia carers proposed a special fund allocation for residential aged care providers and hospitals to reserve beds for this purpose.

- **More innovative models of respite**

- Carers identified the need to fund and introduce more innovative models of respite care. Respite needs to cater for varying needs and preferences of carers. It also needs to be long enough to offer a real benefit. A carer shared their experience of a new respite offering: *“I did go on the new respite program that started last year where the carers and the loved ones go, the Staying at Home Program, which was absolutely amazing, but you only get two nights, three days, you know, a week would have been amazing”* (FG 12).

- **Specific services for former carers**

- Dementia carers discussed the ongoing impact on their health, wellbeing and finances after they were no longer caring for someone living with dementia. This cohort identified the need for ongoing support.

- **Bereavement supports**

- Bereavement supports including counselling (for example, through the Carer Gateway) and grief awareness training for service providers.

- **Formalised welfare check by GPs**

- Formalised welfare check by GPs when the person receiving care has passed away, as carers are likely to have neglected their health. *“It would be lovely once your journey changes that there is some kind of a mental health check plan or something that's initiated by your GP to check on you and see where you're at. What we need to talk about because you spent so long not looking at yourself and probably not looking after yourself that you forget how and you're not used to asking those questions anymore”* (FG 22).

- **More carer support groups**

- More carer support groups, including ones specifically for former carers and others where former carers can participate with current carers and share their wisdom. *“I think we should have support groups for former carers, or with present carers – probably a good idea because we have the experience, we can help them along the way. But I think the government should facilitate more support groups”* (FG 22).

- **A buddy system**

- A buddy system where former carers can have one close peer contact and support each other.

*“My friend and I have a relationship such that we look after each other, and I would advocate that as being part of a solution if you can make it happen. We met when our respective wives went into residential care and from that time on we've looked out for each other within support groups and just as individuals together sharing the journey. So, I guess what I'm trying to say is, if it's possible, if you can get a person other than a support group that you can link with closely and share and basically just look out for each other, I'd be lost without that”* (FG 22).

- **Reconnection with community**

- Reconnecting with community through positive, impactful volunteering opportunities to fill the time and provide a sense of purpose, for example, providing advocacy and support for others.

One carer shared their experience on the benefits of reconnection. *“I found that when my wife passed away, the big hole needed to be filled and within a couple of weeks I was volunteering and continue to volunteer. Now I think the government needs to push the volunteering part of filling that hole for former carers. I think we're short of volunteers anyway, but that's probably a good move”* (FG 22).

- **Improved supports for carers in regional and remote areas**

- No solutions were provided however based on issues identified, more regular specialist visits to rural and remote areas would assist carers and the establishment of a younger onset dementia support group.

As one carer shared, *“it's very hard to get help here (regional SA). The biggest problem is to make contact with the government agencies or whoever may be concerned are usually based in Adelaide and you have to wait until they do a run out*

*this way ... it could be next month, it could be two months” (FG 20).*

- **Improved access to medical services and more help from medical services**
  - It was proposed that dementia-specific medical services should be established. This would include access in one clinic for diagnosis and ongoing treatment - including GPs, specialists and allied health professionals (FG 2).
- **More carer inclusiveness in Home Care Packages**
  - Carers identified that they themselves often needed equipment and home modifications to assist them to perform their caring role. This might include such things as modifications to their cars in order more easily transport the person they were caring for or modifications to their own homes such as railings and ramps. The perception was that home care modifications were unavailable if the person receiving care wasn't residing in the carer's home (FG 2).



## Financial wellbeing of carers

- **Impacts of loss of employment**
  - No specific solutions were identified for addressing financial wellbeing, however workplace flexibility and service providers ensuring their own workforce capacity will assist dementia carers. More broadly, within the caring system, dementia carers identified where dedicated funding packages would assist them greatly, for example with respite care.

# **CARING FOR A VETERAN AND AUSTRALIAN DEFENCE FORCE (ADF) FAMILY CARERS**



# IDENTIFIED ISSUES

*"Carers of veterans want DVA to understand their need for respite and want DVA to take responsibility for providing it so that carers can continue to provide care" (FG 11).*

*"If you're a defence family then they're meant to give you a spot in that school as a defence family that's posting in. But a lot of schools, like if I'm posting, let's say I'm posting to New South Wales and that's a fully zoned state. Whether I'm defence or not doesn't mean I can get my special needs kid into their school" (FG 11).*



## Health, safety and wellbeing of carers

- **Respite**
  - Carers of veterans and ADF family carers need access to respite but many ADF carers described it being 'a dirty word', that neither the NDIS nor the Department of Veteran Affairs (DVA) seem willing to fund.

Some carers of veterans also described being a carer with their own underlying health and wellbeing issues and that respite is essential to allow the carer 'a breath'. Like other cohorts, carers flagged the difficulties in accessing emergency respite (which can be critical for veterans and their carer), compounded by the fact that posting cycles for serving personnel can mean the veteran or another family member requiring care goes to the 'bottom of the queue' for services in their new location.

Veterans can have complex physical and mental health issues and carers often put their own health second to address these complex needs that can compound unexpectedly. One carer in the focus groups is caring for more than one person and shared their experience, "...two members in my family were suicidal and I was in hospital. So what happens then, right? I can't heal because I've got to go home" (FG 11).



## Identification and recognition of carers

- **Carers of veterans want to be seen**
  - Carers feel unrecognised, undervalued and unseen by the DVA. *"The veteran themselves think that DVA is going to look after you"* (FG 11).



## Balancing work, volunteering, education and care

- **Carers needs are not considered when personnel postings are developed**
  - ADF personnel and families with caring responsibilities may not be able to move (post) as quickly as other personnel.

For example, for a serving ADF member with a child with Down Syndrome, the supports may be available in a particular location, and the new posting may not have similar services, making it hard for the ADF member and their family to relocate.

Further, carers being posted to a new location may lose their place in the queue for services and support; by moving, they go to the bottom of the queue again and if they don't receive services within their posting cycle then they keep moving and never get that support.



## Access to quality supports and navigating complex systems

- **Carers of veterans and defence family carers need specific supports**
  - Carers of veterans and carers in defence families have a unique situation in navigating ADF and DVA rules, potentially alongside the NDIS and My Aged Care systems, too.

Non-veteran specific support services often lack training and awareness of veterans with care needs issues, adding complexity to managing care, for example in dementia wards or stroke units. Carers also discussed a lack of training for First Responders on how to support veterans with care needs in an emergency response.

- **Carers of veterans and defence family carers have unique challenges**
  - When families are still engaged in posting cycles, carers described difficulty with medical professionals having a comprehensive understanding of the veteran's medical history. This was often because veterans have previously been treated on base while serving members, and then by private practitioners as veterans, and those private practitioners may not have access to their records.

Constantly moving for postings also means navigating new systems and jurisdictions (potentially new countries) with each move and searching for local supports from scratch each time.

# IDENTIFIED SOLUTIONS



## Health, safety and wellbeing of carers

- **A wellness card for carers of veterans and defence family carers**

- A wellness card could provide access to services and down time; for example, child minding that would help provide added support with it viewed that even basic respite is better than the current situation. It was suggested a wellness card could provide proactive wellbeing management opportunities like gym membership for carers.

*As articulated by one carer, “a national ‘Carer Card’ and database, so when a person is early in their diagnosis stage, if a carer is identified by the GP/health professional, they could write a letter that will get the carer onto the carer database that would help with identification with Centrelink, and when supporting someone to access NDIS/MAC” (FG 11).*

- **Veterans’ Home Care Package**

- A veterans’ home care package would provide added respite and support to carers and those who they care for. The veterans’ home care package could comprise key items needed for carers and their respective support networks (assuming they have them) such as case management, and health plans including mental health plans.

*“We need a veteran’s home care package which includes case management, someone that can develop a wellbeing, medical safety plan for all individuals in the family” (FG 11).*

- **Recognising and treating intergenerational trauma**

- There needs to be an ADF (or DVA) support package for families experiencing intergenerational trauma. This includes defence families and those who rely on them for support.

*“There needs to be an ADF support package for families care as generational trauma and to identify that. They need to look at exactly what’s going on with us as defence boards, families, those who are serving and the generational trauma from that. And it’s critiqued on that because there’s many levels of us” (FG 11).*

- **Access to respite**

- Carers of veterans and defence family carers repeatedly raised respite as a key issue. Carers reiterated the need for specialised care for veterans. Carers want consistent language used – respite, not a break; they want trusted respite with specialised veteran care, for example; and they want to be able to take respite without worry that the person they care for isn’t safe.

Carers want DVA and the NDIS to have appropriate veteran and defence family care, *“there are difficulties getting respite through both the NDIS and the DVA. DVA need to get the idea into their head that carers of veterans need respite and they need to take responsibility for it. NDIS needs to accept that in order to avoid care, responsibilities and cost being shifted to some other part of the system they are better off giving respite, reasonable respite, to carers so that they so they can actually continue to care for the person. And neither of those things happen at the moment”* (FG 11).



## Identification and recognition of carers

- **DVA to recognise carers**
  - Carers of veterans want to be recognised by DVA. There was discussion of previous generations of spouses who simply weren't recognised at all, and carers want to move forward and be seen by DVA.

Not being recognised can create unforeseen complications. *“Being recognised when my dad had heart surgery – mum couldn't get into the DVA car because she hadn't served. We had to go and get her. She had to pay for private accommodation while dad was in having his procedure. So the spouse and spouse carer are two roles, and they are invisible”* (FG 11).



## Balancing work, volunteering, education and care

- **More considered defence force postings**
  - If the ADF was more cognisant of the needs of carers and invested more time and resources to supporting caring families, carers felt that would address some of the ADF's staff retention challenges.

Allowing those with caring responsibilities to deploy to postings where they can fulfill their caring responsibilities would go a long way to winning loyalty and avoid unaccompanied postings (where the serving member deploys to a new location without their family joining them) that can negatively impact family relationships. As one ADF carer expressed, *“a lot of families decide not to post with a serving member because of not being able to access the support for those they care for”* (FG 11).

It was also suggested that receiving notice of a posting 18 months in advance for caring families would allow carers time to plan ahead for services (current posting notice is much shorter).

- **Better integration of portfolios**
  - Carers want better integration of carer supports between portfolios, particularly including DVA for carers of veterans and defence family carers. Without this integration, individual supports become isolated and fail to incorporate other needs.

*“A stronger connection of ADF to DSS other government departments is needed to ensure a complementary nature of services is needed” (FG 11).*

- **Workplace flexibility**

- Workplace flexibility demonstrates to ADF serving personnel and they and their families are valued for their commitment to serve, *“flexibility of support is needed for carers to allow them to stay in generalised work or education as well as in ADF. The ADF is far less flexible than other work environments” (FG 11).*

- **Help with system navigation**

- Veteran and defence family cars want system navigation support, especially when operating across multiple support networks such as NDIA and DVA. These carers also need support to navigate jurisdictional systems as these families tend to relocate more than the average Australian due to posting cycles.

The need was summarised well by one carer: *“Carers need someone who will help them to navigate systems rather than having a long list of stuff that you've got to go through individually and tick off. You need to talk to someone who listens to what the person's needs are and then starts saying, ‘oh ,okay, sounds like you need this and that. Can I help you with navigating to get you support?’ And that's a really critical role” (FG 11).*

## OTHER CARING THEMES



# IDENTIFIED ISSUES

*“When suddenly becoming a carer, it can be difficult, overwhelming and confusing.” (FG 5)*

## Health, safety and wellbeing of carers

- Carers are overtired

- Both young carers and carers in regional locations commented on the 24/7 nature of their caring role. They commented that that it was difficult to find time for themselves, have inconsistent sleep and found themselves getting overtired. A similar situation was also identified by dementia carers.

A carer under the age of 18 was open in sharing, *“I think I face most of the challenges of getting overtired as much because it's 24/7 caring for my brother, and I find that he can be very hard to deal with, after a long time, you just get very tired”* (FG 3).

Caring and working, especially when support services are limited, adds to a carer's exhaustion. *“It's like you work and are a carer, so you never knock off. You never have downtime. Never”* (FG 13).

Regionally based carers felt that combining overtiredness with the complexity of the caring role increased their stress levels and found it difficult to get into a good head space. They felt their mental health and wellbeing was adversely impacted.

*“I was just thinking of when you look at all of these things like the financial impact, the time it takes, taking care, the stress, it all goes to your mental health and wellbeing because all of that puts stress on you, which affects your sleep, which affects your caring role. It's very hard to get something that's just going to get you really, really into a good head space”* (FG 6).

- Caring for multiple people at one time

- Regional carers caring for multiple people within a family unit found it difficult to have the knowledge and know-how to approach different care needs for each individual in their care. They commented on the range of skills you need to be able to cope. Carers found making decisions in these environments difficult and found the situations isolating.

This can involve caring for people living with very different disabilities and support needs. *“I look after my 36-year-old daughter with William Syndrome, and that's fairly rare. It's mainly intellectual disability and some physical problems; also, my 95-year-old mother who's got short-term memory loss. So, my issue is, often you just don't have the skills to cope with two very different people with different needs. And, also, there seems to be quite a bit with Carers Victoria – quite a bit of information about respite for the elderly, but not for disabled younger people”* (FG 4).

It can also involve trying to manage multiple people in one household, and the difficulties of this can be compounded when in a regional or remote area with less support services. *"I care for my two children who are both autistic and ADHD. I have one that's inattentive and one that's hyperactive. And I also care for my husband, who has major depression with psychosis. So, it's almost like having a third child. And I find this challenging and isolating, and I don't know what to do. Say, not knowing what to do or say. Not even knowing how to care or help them in their time of need. And that's what I find challenging"* (FG 4).

- **Carers under the age of 18 years**

- Young carers commented that there was often the need to care for a parent as well as a sibling, such was the impact of the caring requirements of their sibling. This results in the young carer looking after multiple family members.

One young carer reflected on their responsibility: *"I feel like caring for my sister, but also caring for my mum because she does so much and she does it all on her own, mentally and financially. I don't know, I wish my mum got a bit more recognition for who she is and what she does. And I just have a lot of respect and love for her. She's my biggest role model in life. So, yeah, caring for my sister, but also looking after my mum at the same time, helping chores and making sure that she gets a break"* (FG 4).

Young carers found it hard to manage social activities with friends due to their caring responsibilities. *"It's really hard to manage social activities with your friends because you always have to take care of the person you're caring for. It's hard to go out with your friends and spend time with them"* (FG 1).

- **Carer stress impact on household and relationships**

- Carers found it difficult to not be impacted by their caring responsibilities; this had flow-on impacts on others. It is hard not to think how the person they are caring for is going at any given time, and this can impact their own behaviours and decisions.

This stress can impact a carer's relationship with others within their household, their family, social networks and within the community. This was discussed as a significant issue for dementia carers, and it was also highlighted in discussions with regional and remote carers, and young carers.

- **Regional and remote carers**

- Carers noted they are always thinking about the person they care for. *"I feel like there's always a part of me in the back of my mind thinking about how my sister's going. There's always that thought, because I feel like I have that responsibility. The toll that it has on the household ... and in general, I feel like being a carer there's a big responsibility and, obviously, as a family, we want to make sure that we can support our sister in the best way"* (FG 7).

Regional carers also commented that when children are left at home, when someone was left caring for their ageing spouse, and support from friends dwindled, carers

were left feeling isolated.



## Education and life skills for carers

- Education

- Carers under 18 years of age commented that focusing on their education, particularly at exam/assessment time was particularly difficult. All the tasks can become overwhelming and young carers worry about the person they're caring for when they're in the classroom. At times it is difficult to catch up on information.

Teachers often do not understand the impact of being a young carer. *"Some teachers aren't really empathetic. I've seen some teachers, they don't really care. They say, 'Oh, life just gets harder, get over it.' But sometimes it's not the case. I feel like school education needs to let all teachers be aware, there are kids that are in this situation that are struggling, so that the school can provide extra help to young carers"* (FG 3).

Young carers also found it hard to find time to play sport, relax or spend time with friends. *"I have to sacrifice my lunch and recess, my break to study and ask questions of my teachers. So that has been a real problem, because I want to play sport, play basketball, sit down and relax, but that's not possible because I have to study"* (FG 3).

- Life skills

- Carers commented that caring presented situations they had not faced before. *"I'm not a professional. I don't know how to handle this"* (FG 18). They felt they were not equipped with the psychological support or practical skills to be able to support their own self-care or for the person they are caring for.

As a dementia carer summarised, *"this man is not the man that I married, and I have been a partner to for 54 years. This is something that I've never experienced before"* (FG 18).

Carers felt there was an element of risk using existing supports, such as an Employee Assistance Program (EAP) through their place of employment. A dementia carer was worried, *"... it was very risky because if people go to an EAP program, although you're anonymous, you still know if somebody's going to an EAP program, it can still say, 'oh, they're not quite up to the job'"* (FG 18).

Carers described poor experiences when using known support services unless lucky enough to contact a particular person who was knowledgeable. The lack of consistency with support services is frustrating for many carers and reduced the confidence of carers when liaising with this service. A lack of quality support and advice also increases the administrative burden on carers, as they continue to seek out other options to improve their own knowledge base.



## Identification and recognition of carers

- **Gender balance**

- Carers commented on the impacts of women traditionally taking on caring roles. Seven out of ten carers are women. In particular, regional and remote female carers felt that if they had been out of the workforce for other reasons and were again required to be out of the workforce due to a caring role, this created a 'stop-start' pattern that impacted their employment potential and superannuation. They felt the impact of this pattern was not recognised by Government.

Gendered views on caring roles are felt by many female carers. *"If you had children, then you're out of the workforce for a period. Then if you're caring for your husband, parent, partner, you might've gone back to work for a little bit, but then you're out of work again"* (FG 10).

- **Inconsistent recognition across government systems**

- Carers identified inconsistencies in what support can be accessed across services like the NDIA and My Aged Care, including residential respite supports. Carers felt it was about *"one system potentially valuing the caring role more than another system"* (FG 10).



## Balancing work, volunteering, education and care

- **Workforce challenges**

- Carers noted the need to stop paid work, change career (due to lack of flexibility), or reduce working hours. Carers felt they experienced conscious and unconscious bias due to career breaks and leave required due to their caring responsibilities. This was particularly noted by regional and remote women (discussed above).

A dementia carer summarised their experience with changing jobs and lack of carer progression opportunities. *"I found employment very close to home and instead of working five days a week, I was working four. I was offered, probably only once or twice, promotions, but other promotions came up and I was never offered them because I couldn't take them anyway. I had to decline promotions. It was a job that I really wanted to do, and would've done well"* (FG 18).



## Access to quality supports and navigating complex systems

- **Inconsistent support from government services**

- Carers need consistent people-centred support from government services; not having this adds to the stress of caring and to the time required to organise care. Some carers identified they have given up liaising with some services altogether. A regional carer noted their *"... LAC is useless and I won't even engage with them because they're so useless"* (FG 7). The impact of this on a regional and remote carer can be even more significant than for a metropolitan carer.

- **Housing stress**

- Housing stress can be a significant issue for some carers, especially if the house they are living in is connected to supporting the person being cared for. This is across the board for those with mortgages, wanting to buy, renting or in social housing. This is a highly emotional situation for some carers. *"I'm looking here about housing for unpaid carers; in my case, we lost the house, so all we have is housing from government disability. And if I can't look after my husband anymore and he goes into a carer facility, then because the place is special for disabled people, I don't know"* (FG 9).

Some carers find themselves needing to move to seek the support they need. *"We've had to move, sell a property, uproot from a very established little environment and all the social groups in a little tiny town to come here, 400kms away, to get support"* (FG 17).



## Financial wellbeing of carers

Ongoing financial challenges were raised as a significant issue for many carers. These challenges were created by a variety of situations. They included travel and medical costs, future impacts of not being able to pay down a mortgage or inability to buy essential resources, such as a computer. One carer described the financial impact as being in a *"poverty cycle"* (FG 4).

- **Young carers**

- Carers under 18 years of age find employment can be important as an 'escape' from their caring role. It gives young carers income that offers them the freedom to do activities with friends and provides a sense of independence. However, employment can also create a sense of guilt when caring responsibilities impact on the young carer's ability to meet workplace requirements, for example, providing late notice to an employer about not being able to attend a shift.

Whilst some employers are understanding, young carers still feel a sense of guilt. *"Even though my boss is understanding most of the time, I have to pull out of work a lot on very short notice because there's an emergency at home ... it makes me feel bad"* (FG 3).

- **Government financial impacts**

- Government supports can assist with the costs of caring and the cost of not being able to work as desired or required. However, many carers stated they were not aware of their entitlements, that government supports are too low or 'tokenistic', and the red tape to access benefits or entitlements can be cumbersome. *"The car allowance is there, and that's nice, and that's easier to get. You don't have to be means tested to get that, but it doesn't mean everybody gets access to it because there's a whole heap of criteria you still need to meet"* (FG 10).

Carers proposed the government should consider financial support of carers from an economic lens; for example, the financial benefit to the economy of caring for

someone at home rather than having them in residential care. *“It should actually be to the economic interest of Australia because the difference between having a person in care and having them at home is quite a big financial difference”* (FG 10).

Carers also question the administration fees charged by providers, especially when service provider staff are not well paid. A carer shared their frustration: *“When you first get your allowance for the person you're looking after, you think, geez, that's a lot of money. Half of it goes to administration straight away because you are paying the organisation that you've got your support workers through \$70 an hour. The support worker gets half that. What administration fees are coming out of that on an hourly base?”* (FG 4).

## IDENTIFIED SOLUTIONS



### Health, safety and wellbeing of carers

Carers identified the importance of being able to network with other carers and have peer support. Networking did not require a focus on caring responsibilities; some carers identified having a place to go as equally important. *“If you want someone to talk to, if you want to get advice, support, information, anything, there are people there that you can talk to. Or if you just want to go and just read a book, which I've done many, many times”* (FG 7).



### Education and life skills for carers

Carers identified many ways where they could be better supported with education and life skills to assist them in their caring role. Many have been identified above, but additional recommendations include:

- **EAP for carers**
  - Whilst some services provide counselling services, carers identified the need for a Carer EAP. This would also assist in recognising the importance of their role, which many view as a job. A frustrated carer expressed their view: *“So if it's good enough for an employee to have an EAP program, surely it's good enough for a carer to have a volunteer EAP program because we are volunteering our care in the workforce of the person we are looking after”* (FG 18).

- **Carer grants**
  - Carers are prepared to set up support networks within their community, but they need funding to do this. One carer observed, *“They've got grants available. They're more focused at Aboriginal and Torres Strait Islander groups. (What) if we could apply for a grant for \$25,000 to set up a group for an hour once a week, an hour once a fortnight, where we could all come together, network, sit down, have tea, chat. That's what I need as support”* (FG 7).
  
- **Respite**
  - Carers want the flexibility to choose respite that works for them and their families. One carer proposed more flexibility through Gateway or financial support so carers can individualise their respite – a yoga or pottery class were provided as examples (FG 5).

Carers also identified the benefit of being able to share respite together. *“At our carers retreat, we had a mum and a son who came along to because they care for their (shared family member). And it was so beautiful to watch them bond together”* (FG 6).



## Identification and recognition of carers

- **National Carer Identification Card**
  - The idea of a national carer identification card has been raised in multiple focus groups. Carers proposed an identification card could result in notifications being triggered in broader government systems to provide the support and advice carers require.

Their concept is *“a national ‘Carer Card’ and database. When a person is early in their diagnosis stage, if a carer is identified by the GP/health professional, they could write a letter that will get the carer onto the carer database. That would help with identification with Centrelink, and when supporting someone to access NDIS/MAC”* (FG 5).



## Balancing work, volunteering, education and care

- **Resources to help carers under the age of 18 explain their role**
  - Resources to assist young carers explain their caring role will reduce the assumptions and misunderstandings that they can experience in the education system. This could also be supplemented by ‘wellbeing officers’ who coordinate extensions/extra support and help young carers with time management (FG 3).
  
- **Carers leave**
  - It was proposed that carers should have a carve out with how carers leave is treated against other personal leave (FG 7).



## Access to quality supports and navigating complex systems

- **Carers under 18 years of age**

- Young carers provided useful insights to the supports they need, including support organisations and networks targeted at young carers, culturally inclusive programs, and awareness of available programs. The benefits of socialising with other young carers are significant. *“When you're around other carers, you know there's someone like you, going through the same thing as you. It's easy to relate to them and you can actually talk to them”* (FG 3).

- **Services Australia and the Carers Gateway**

- Carers who work full-time want more flexible hours to access Services Australia so they can attend with the person they care for in-person. *“If you have managed to return to full-time work, then you really need the services to be open and able to talk to you out-of-hours. So the fact that I can't go to Centrelink before 8:30am, and then you have to wait, and they shut at 4:00pm ... I would like to be able to do some of these things out-of-hours when I can sit with my dad and he and I can work together”* (FG 6).

Carers also want to see better trained Services Australia officers who can assist them without contact referrals or provisions of conflicting information.

Better transparency in Carers Gateway will better enable carers to identify services they are entitled to access (FG 17).



## Financial wellbeing

- **Carers under 18 years of age**

- Young carers noted that a public transport subsidy will assist them in their caring role.

# BACKGROUND

For the purposes of this report, 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	URBAN, REGIONAL, REMOTE	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	53	WA	Urban	41	No	0-19 hours per week	Casual	90yo with dementia
2	74	WA	Urban	4	Yes	50+ hours per week	No	Brothers, sisters and husband. Complex health problems
3	35	WA	Urban	17	Yes	50+ hours per week	No	Mother, grandfather and grandmother
4	69	WA	Urban	45	Yes	50+ hours per week	No	Mother – disability; father – dementia
5	74	WA	Urban	67	Yes	20-49 hours per week	Retired	First I cared for my father (dementia) then my mother (frail aged) now my partner (dementia)
6	47	WA	Urban	10	It's complicated	20-49 hours per week	Full-time	Both ageing Parents. Alzheimer's disease, kidney transplant patient, deaf, type 2 diabetic, Atrial Fibrillation.
7	72	WA	Urban	64	Yes	50+ hours per week	No	Husband has vascular dementia, diabetes, blocked carotid and leg arteries, atrial fibrillation
8	47	WA	Urban	43	Yes	50+ hours per week	Casual	Mother, frail and dementia (aged)
9	51	WA	Urban	47	Yes	50+ hours per week	No	Mother, cognitive decline and mobility limitations

#	AGE	STATE	URBAN, REGIONAL, REMOTE	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
10	58	WA	Urban	52	No	20-49 hours per week	Fulltime	Mother, to improve her quality of life and to ensure she is receiving the best medical care and can participate in social activities
11	14	VIC	Urban	11	Yes	20-49 hours per week	I am not	My sister and mum; help with mental health issues
12	16	VIC	Urban	11	Yes	50+ hours per week	Yes, parttime	Younger sister - she has a mental disability
13	15	VIC	Urban	13	Yes	50+ hours per week	No	My mother with carpal tunnel illness and in general - her tiredness from a lack of time management
14	13	VIC	Urban	12	Yes	0-19 hours per week	Unemployed	Mother and sister
15	18	VIC	Urban	15	Yes	20-49 hours per week	No	Mother due to illness
16	17	VIC	Urban	16	Yes	0-19 hours per week	Casual	Father
17	13	VIC	Urban	11	Yes	0-19 hours per week	No	Mum, disability
18	18	VIC	Urban	11 years old	It's complicated	0-19 hours per week	Unemployed	Brother. He has ASD, OSD, PTSD which make his everyday life hard, as he struggles with sensory issues and remembering to eat, drink, care for himself
19	16	VIC	Urban	13	Yes	0-19 hours per week	Casual employment in hospitality	Mum, who suffers from a number of chronic and degenerative disabilities
20	15	VIC	Urban	10	Yes	0-19 hours per week	Not employed	My brother and I provide care because of multiple disabilities
21	18	VIC	Urban	8	Yes	0-19 hours per week	Casual	Older sister; they have ASD
22	16	VIC	Urban	10	Yes	20-49 hours per week	No	Younger brother, he has ARFID, ASD, anxiety and chronic health conditions
23	14	VIC	Urban	12	Yes	20-49 hours per week	No	Disability
24	8	VIC	Urban	7 years	Yes	0-19 hours per week	No	Mom
25	12	VIC	Urban	10	Yes	0-19 hours per week	No	Brother - intellectual disability and autism

#	AGE	STATE	URBAN, REGIONAL, REMOTE	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
26	17	VIC	Urban	10~11	Yes	20-49 hours per week	No	Mum and sister
27	57	VIC	Regional	45	No	0-19 hours per week	No	
28	53	VIC	Regional	45 years	No	50+ hours per week	Self-employed	
29	52	VIC	Regional	48	It's complicated	50+ hours per week	Full-time carer	
30	67	VIC	Regional	30ish	Yes	50+ hours per week	Part-time	
31	53	VIC	Regional	44	Yes	50+ hours per week	Part-time	On extended carers leave
32	69	VIC	Regional	59	Yes	50+ hours per week	No	
33	65	VIC	Regional	28	It's complicated	50+ hours per week	No	
34	56	VIC	Regional	32	Yes	50+ hours per week	No	
35	35	VIC	Regional	23	Yes	50+ hours per week	Casual	
36	58	VIC	Regional	35	Yes	50+ hours per week	Self-employed, Casual up to 10 hours per week	
37	67	VIC	Regional	36	Yes	50+ hours per week	No	
38	65				Yes	50+ hours per week	No	Wife, dementia
39	46	TAS	Urban	41	Yes	20-49 hours per week	Part-time	Full-time carer for husband who had a severe stroke & has ongoing disabilities directly related to this
40	70	TAS	Urban	50	Yes	50+ hours per week	No	Husband and 34yr old son who both have Huntington's Disease
41	57	TAS	Urban	33	Yes	50+ hours per week	No	Brother, mental health; mother Parkinsons; father, dementia
42	42	TAS	Urban	33	Yes	50+ hours per week	No	Disability
43	34	TAS	Urban	30	Yes	50+ hours per week	Not employed	Wife and kids - mental health, congenital heart disease
44	57	TAS	Urban	12 years old	It's complicated	50+ hours per week	Part-time police officer	Complex needs young dementia
45	60	TAS	Regional	54y officially	No	0-19 hours per week	Full-time	My father only now, my mother recently died issues relate to neurocognitive illness.
46	55	TAS	Regional	24	It's complicated	20-49 hours per week	Part-time	Disability, mental health, chronic illness, degenerative illness

#	AGE	STATE	URBAN, REGIONAL, REMOTE	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
47	48	VIC	Regional	36	Yes	50+ hours per week	No	Parent of neurodivergent children
48	71	VIC	Regional	59 years old	Yes	50+ hours per week	Retired	37yo son who has a mental illness
49	41	VIC	Regional	27	Yes	50+ hours per week	No	2 ASD children
50	48	VIC	Regional	35	Yes	50+ hours per week	No	Mum and daughter. Mental illness and elderly chronic illness and degenerative illness
51	56	VIC	Regional	35	Yes	50+ hours per week	No	Adult son who has a disability
52	77	VIC	Regional	23	Yes		No	Daughter, disability; Secondary carer, grandson, disability
53	71	VIC	Regional	59 years old	Yes	50+ hours per week	No	37yo son who has a mental illness
54	55	VIC	Regional	39	Yes	50+ hours per week	Part-time	Son, ASD
55	71	VIC	Regional	62	Yes	20-49 hours per week	Retired	Alzheimer's and Vascular Dementia
56	41	ACT	Urban	31	Yes	50+ hours per week	Full-time	Husband with uncontrolled epilepsy and our foster daughter with significant disability
57	34	ACT	Urban	29	Yes	50+ hours per week	Full-time	Child
58	47	ACT	Urban	27	Yes	50+ hours per week	Part-time	Daughter with Rett Syndrome
59	48	ACT	Urban	47	It's complicated	20-49 hours per week	Not employed	Mum who is hemiplegic following a severe stroke, and my teenage son who suffers from depression
60	67	ACT	Urban	50	No	0-19 hours per week	Yes; I run my own Business	Mother
61	68	WA	Urban	53	Yes	50+ hours per week	Casual work	Mental health
62	65	WA	Urban	6	No	0-19 hours per week	Casual	Mother for mental health; father for Parkinsons; brother #1 for substance abuse; brother #2 for chronic illness; mother-in-law for breast cancer; father-in-law for Melanoma; husband for mental illness; son for mental illness
63	67	WA	Urban	52	No	0-19 hours per week	No	Daughter, mental health and cancer

#	AGE	STATE	URBAN, REGIONAL, REMOTE	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
64	71	WA	Urban	54	No	0-19 hours per week	Voluntary only	Sister, borderline personality disorder with chronic self-harming; elderly woman [now 98]; several friends with mental health conditions
65	61	WA	Regional	30	It's complicated	50+ hours per week	Part-time mental health recovery support	Mother, aged care – unpaid; 2x male clients in SIL accommodation with schizophrenic disorders and CTO – paid part-time. Past: brother, AOD issues, undiagnosed mental health conditions, diagnosed Korsakovs Syndrome
66	73	WA	Urban	65	Yes	0-19 hours per week	Retired	Wife - mental health, chronic condition, and degenerative disease
67	53	WA	Urban	35	Yes	0-19 hours per week	Full-time	Husband: chronic depression Daughter1: substance misuse Daughter2: learning disability
68	53	WA	Remote	21	Yes	20-49 hours per week	Full-time	Disability and mental health
69	38	WA	Urban	19	Yes	50+ hours per week	No	Son (ASD, ADHD, anxiety)
70	72	WA	Remote	48	No	0-19 hours per week	No	Daughter, mental health
71	64	WA	Urban	60	Yes	50+ hours per week	No	Son – autism, mental health
72	57	WA	Urban	32	Yes	50+ hours per week	No	Daughter, intellectual disability and psychosocial disability
73	38	WA	Urban	20	Yes	50+ hours per week	Not employed	18yo son, autism and ADHD. My youngest son also has ADHD. I have also previously cared for my elderly father who had both physical illness, disability and mental health struggles

#	AGE	STATE	URBAN, REGIONAL, REMOTE	AGE BECAME CARER	LIVE W/ WHO YOU CARE FOR	HRS/AWK CARING	EMPLOYMENT STATUS	WHO DO YOU CARE FOR AND WHY DO YOU PROVIDE CARE
74	73	WA	Urban	65	Yes	0-19 hours per week	Retired	Wife - chronic illness, degenerative illness, mental health
75	65	WA	Remote	36	Yes	50+ hours per week	Carer Rep through CWA	Husband since 1996, sister for bipolar and substance abuse since 2015
76	55	SA	Regional	37	Yes	50+ hours per week	No	Grandson, disability; husband dementia
77	68	SA	Regional	57	Yes	20-49 hours per week	No	Granddaughter
78	52	SA	Regional	34	Yes	50+ hours per week	Ne	Son, autism
79	43	SA	Urban	27	Yes	50+ hours per week	Part-time, nurse ED	Child with ASD, cardiac and respiratory issues
80	73	SA	Urban	23	Yes	50+ hours per week	No	Husband - Vietnam Veteran with PTSD, heart condition, emphysema, prostate cancer and severe arthritis
81	57	SA	Urban	42	Yes	50+ hours per week	I'm on incapacity payments from DVA and am a non-fiction author	Two sons, both have autism spectrum disorder, one also has borderline personality disorder and the other also has an intellectual disability
82	58	SA	Regional	2014	No	0-19 hours per week	No	Veteran husband who suffered PTSD and alcohol misuse disorder
83		SA		2019	Yes	20-49 hours per week	Not currently employed	Wife, cooking, mental health
84		SA		67	No	20-49 hours per week	Not currently employed	Wife, dementia
85		SA		73	No	0-19 hours per week	Casual	Husband with dementia
86	42	SA	Regional	34	Yes	50+ hours per week	Full-time	Son, on the spectrum
87	62	SA	Regional	48 years	No	0-19 hours per week	Part-time	26yo daughter who lives with physical disability, chronic illness and mental health concerns. My 85yo mother who lives with a number of physical challenges and mental health concerns

#	AGE	STATE	URBAN, REGIONAL, REMOTE	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
88	51	SA	Regional	27	Yes	50+ hours per week	Casual	Son 26yo – ASD, ADHD mental health; son 15yo – ADHD, mental health; son 15yo – ADHD
89	34	SA	Regional	33	Yes	50+ hours per week	No	Daughter, cancer
90	68	WA	Regional	39	Yes	50+ hours per week	Not currently employed	Two sons with disabilities and mum, dementia
91	80	WA	Regional	65	Yes	20-49 hours per week	Employed, Casual	Husband - emphysema and cancer; friend – Alzheimer's
92		NSW		71	Yes	50+ hours per week	Not currently employed	Wife, Vascular Dementia
93		NT		64	Yes	20-49 hours per week	Not currently employed	Husband, Alzheimer's
94		NT		68	No	0-19 hours per week	Not currently employed	Husband, dementia
95		NT		67	Yes	50+ hours per week	Not currently employed	Friend, dementia
96				43	Yes	50+ hours per week	Not currently employed	Initially parents-in-law both with dementia (one Alzheimer's, one Lewy Bodies); subsequently husband (Alzheimer's)
97				55	No	20-49 hours per week	Not currently employed	Husband, Alzheimer's
98				41	No	0-19 hours per week	Not currently employed	Mother, dementia
99		SA		48	It's complicated	0-19 hours per week	Casual	Mum who has frontal temporal dementia; previously cared for sister, mental health condition, and dad, substance addiction
100		NSW		56	Yes	20-49 hours per week	Part-time	Partner, frontal temporal dementia
101		NSW		40	No	20-49 hours per week	Casual	Aged care, dementia care for father (now deceased) and mother
102	71	NSW	Remote	58	Yes	50+ hours per week	Part-time	Husband, dementia
103	66	NSW	Regional	58	Yes	50+ hours per week	No	Daughter; both parents (father, stroke & vascular dementia; mother, Lewy Bodies, dementia)

#	AGE	STATE	URBAN, REGIONAL, REMOTE	AGE BECAME CARER	LIVE W/ WHO YOU CARE FOR	HRS/AWK CARING	EMPLOYMENT STATUS	WHO DO YOU CARE FOR AND WHY DO YOU PROVIDE CARE
104	83	NSW	Regional	63	Yes	50+ hours per week	Retired	Wife, dementia
105	71	NSW	Regional	46	No	0-19 hours per week	No	Mother and father
106	83	NSW	Regional	70	Yes	50+ hours per week	Retired	Husband, dementia
107	72	NSW	Metro	55	Other (please specify)	20-49 hours per week	Retired	Husband, Younger Onset Alzheimer's Disease
108	83	NSW	Remote	68	Yes	50+ hours per week	No	Husband; dementia, disabled
109	58	NSW	Regional	51	No	0-19 hours per week	Full-time	Father, dementia
110	80	NSW	Metro	74	Yes	50+ hours per week	Retired	Spouse, dementia
111	66	NSW	Metro	61	No	0-19 hours per week	No	Daughter, frailty/chronic illness/cognitive decline
112	75	NSW	Metro	62	Yes	50+ hours per week	No	Husband
113	71	NSW	Metro	60	No	0-19 hours per week	No	Aunt
114	32	VIC	Urban	28	Yes	20-49 hours per week	Part-time	Grandmum, Parkinsons
115	39	TAS	Regional	30	No	0-19 hours per week	Part-time	Cared for a lot of people. From indigenous persons and now I'm caring for a woman with Alzheimer's disease
116	60	WA	Urban	45	Yes	20-49 hours per week	Part-time	Chronic illness
117	31	SA	Urban	23	Yes	0-19 hours per week	Part-time	LBGTQIA+ housemate; we both live with Autism, ADHD and have recovered from substance abuse
118	27	NSW	Regional	20	No	50+ hours per week	Casual	Heart failure secondary to hypertension
119	54	NSW	Urban	35	No	20-49 hours per week	Part-time	Mental health
120		NSW	Regional	58	Yes	50+ hours per week	Part-time	Husband with dementia
121		NSW	Regional	58	Yes	50+ hours per week	No	Daughter. Cared for both parents; father - stroke & vascular dementia; mother - Lewy Bodies, dementia
122		NSW	Urban	63	Yes	50+ hours per week	Retired	Wife, dementia

#	AGE	STATE	URBAN, REGIONAL, REMOTE	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
123		NSW	Urban	46	No	0-19 hours per week	No	Mother – stroke and dementia years; father – Alzheimer's
124		NSW	Urban	70	Yes	50+ hours per week	Retired	Husband, dementia
125		NSW	Urban	55	Other	20-49 hours per week	Retired	Husband – Younger Onset Alzheimer's
126		NSW	Urban	68	Yes	50+ hours per week	No	Husband – dementia, disabled
127		NSW	Urban	51	No	0-19 hours per week	Full-time	Father, dementia
128		NSW	Urban	74	Yes	50+ hours per week	Retired	Spouse, dementia
129		NSW	Urban	61	No	0-19 hours per week	No	Daughter, frailty/chronic illness/cognitive decline
130		NSW	Urban	62	Yes	50+ hours per week	No	Husband
131		NSW	Urban	60	No	0-19 hours per week	No	Aunt
132	67	ACT	Regional	50	Yes	50+ hours per week	Not currently employed	Late wife, Alzheimer's and renal failure



## 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)