



In-Depth Interviews

NATIONAL CARER STRATEGY
CONSULTATION: JULY 2024



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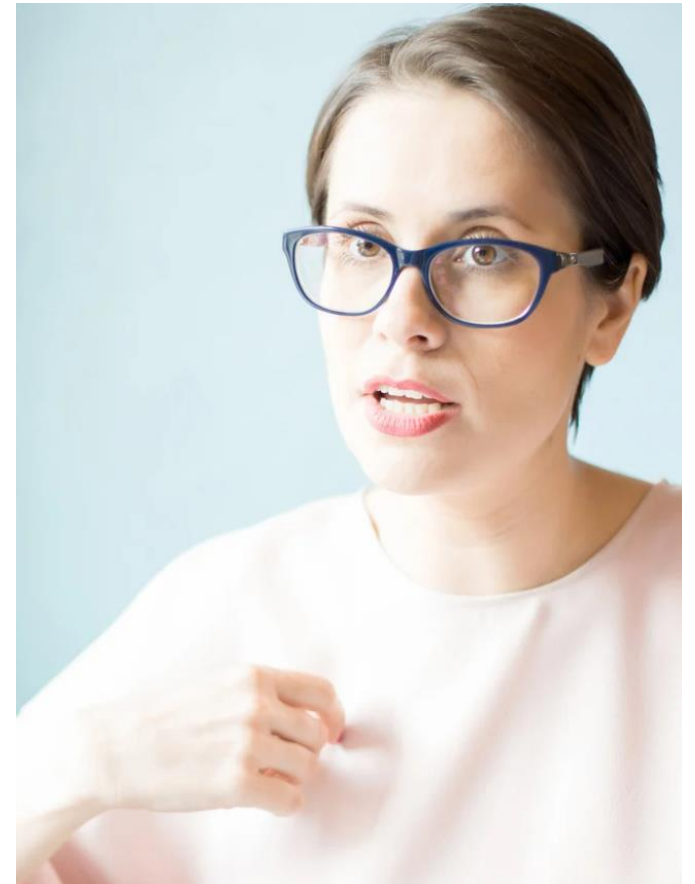


ABOUT THIS DOCUMENT

The research

Carers Australia has been engaged by the Department of Social Services to organise a series of consultations with carer cohorts and stakeholders in the carer domain.

This report documents the insights gathered via in-depth interviews with carers, facilitated during July 2024.



ABOUT THE INTERVIEWS

One-on-one interviews were conducted with nine carers in July 2024 to gain in-depth insights into a variety of caring roles and challenges.

Interviewees cared for people who were;

- Veterans
- Living with Dementia
- Living with Younger Onset Dementia
- Living with Mental Health conditions

Carers were located in metropolitan, regional, and remote locations. One interviewee cared for people who identified as First Nations people.

The interviews were conducted via phone or virtually (depending on carer preference) and took approximately 1.5hrs each.

Key areas discussed with participants:

1. Carer financial impacts
2. Carer health and wellbeing
3. Carer support services – awareness and access
4. Possible solutions that could be implemented to improve the caring experience

Carers Australia would like to thank everyone who participated in these interviews.

EXECUTIVE SUMMARY

Whilst the lived experience of every carer is unique, there are common challenges faced by all carers. The in-depth interviews identified some of these shared challenges and provided possible solutions for inclusion in the National Carers Strategy.

“And when you exceed your bandwidth, the thing that gets lost is not the caring, it's the caring for yourself.”

Removing barriers, and respecting and caring for the carer, are key to their empowerment and wellbeing. Addressing the system within which they operate will drive this change. Improvements identified by Interviewees included:

Better navigation and responsiveness of government systems

- Minimising the need for carers to make impossible choices for their care recipient and themselves (one or the other, education or caring, social support or personal care)
- Reducing the red tape burden, improving agility of service providers, and future proofing care (better support for changing carer needs over time)
- Ensuring high quality, respectful and empathetic (soft skills) service providers

Better support for carer wellbeing

- Recognising the Human Rights and wellbeing of the carer
- Respecting the carer's contribution and knowledge
- Provision of fit-for-purpose respite and support to support carer wellbeing
- Geographical equality; ensuring all carers have what they need no matter their location

SECTION ONE

WHAT WE HEARD

“Managing the NDIS is a full-time job.”

A man with short dark hair, wearing a blue and white plaid shirt, is seen from behind, sitting at a long wooden table. He is surrounded by other people, some of whom are also seated at the table. The setting appears to be a meeting or a collaborative work environment. The lighting is warm and focused on the table area.

CARERS

What are their identified challenges and needs?

Concerns

LACK OF SUPPORTS

"But all I wanted to do is to be the best for my mum, especially as I thought she had to go into aged care. There was no supports there for anything like supported decision making or putting a pool fence around her house to stop a roaming or that sort of thing."

LACK OF ENGAGEMENT

"Government organisations are supposed to have all these policies and programs to support people like this, but they didn't then and they weren't going to, they were looking for any excuse to get rid of you."

HIGH CARE NEEDS

"I have to help him with personal care, because he hasn't been able to do personal care for himself. I've had to feed him because he's just not able to feed himself anymore because he's lost the all of his motor skills."

CARE MANAGEMENT

"We've engaged support workers through the NDIS, honestly, managing the NDIS is a full-time job."



Solutions

RESPECT

"I want the respect that I have given up so much of my life."

RECOGNITION OF DIFFERENCES

"There's a difference between physical disability and mental disability. They need to start recognising that mental health disabilities are separate to those that are suffered (by someone who) has cerebral palsy. There needs to be an understanding around that. I think for far too long there's been a one-size-fits-all attitude."

DISCRETIONARY CARERS LEAVE

"Why isn't there discretionary leave that is catered for people who have caring responsibilities? I have raised this with my local MP."

FORWARD PLANNING

"My neighbor is 85 and he's caring for his wife that's got dementia. She's in a bad way. We met the other day at the letterbox and had little talk and he just said the same. 'Whatever you do, whatever you think X is going to need in the future, put that in place now'."

INSIGHTS AT A GLANCE: CHALLENGES FACED BY CARERS

INSIGHT 1

Contribution of carers ignored

INSIGHT 2

Unfair choices for carers

INSIGHT 3

Administrative burden (red tape) on carers

INSIGHT 4

Ability of system to respond to changing carer needs

INSIGHT 5

Inadequate access to service providers and respite

INSIGHTS AT A GLANCE: OPPORTUNITIES TO LEVERAGE

INSIGHT 6

Government /service providers engaging
with carers

INSIGHT 7

The Human Rights of respite care

INSIGHT 8

Better supported self-care for carers

INSIGHT 9

Geographical equality

SECTION TWO

WHAT DOESN'T WORK:

“When you exceed your bandwidth, the thing that gets lost is not the caring. It’s caring for yourself.”



INSIGHT 1:

Contribution of carers ignored

Carers interviewed feel that they suffer just as much, if not more, than those they care for. In many instances carers are responsible for the welfare and wellbeing of those in their care. Carers are often responsible for the administration of paid and unpaid care which can become burdensome due to its complexity.

Unless government programs are targeted to minimise the impact of caring responsibilities on both the carers and those being cared for, carer wellbeing will suffer. Service providers do not always display adequate empathy or engage with the carer about how best to support the care recipient.

Support for carers' physical, mental, emotional and financial health is needed. Carer burnout increases the need for government funded care for both the carer and care recipient. Like the care recipient, carers value individualised and personalised care.

“Government organisations are supposed to have all these **policies and programs** to support people like this, but they didn't then and they weren't going to; they were looking for any excuse to get rid of you.”

“None of us are after that recognition so much. **We do it because we love them.**”

“**We're really harsh on ourselves.** It's a hard habit sometimes to break but its a reflection of being a caring person, when you want to do something for others and tend to be a bit neglectful of ourselves.”

INSIGHT 2:

Unfair choices for carers

One interviewee indicated that carers can be in situations where they are faced with impossible choices that can cause trauma and regret for carers, the care recipient and others family or friends. Carers want what is best for whomever they care for and only seek the means to do so conveniently and safely with minimal impact when compromise is required.

Carers can also be in situations where they make compromised decisions about themselves, for example, if a young carer is both studying or training, and caring, they need support to do both. Having to choose between education and caring can have long term detrimental impacts for the carer, the broader community and the economy.

Carers appreciate the assistance they and their care recipient receive, however better user-led delivery could better enhance outcomes.

“Yeah, I think it's always good to be reminded that there are people **worse off than you** are. I think that's important.”

“One of the things is we're expected to not be working full-time to get the carers pension, yet the **carers pension is so poorly funded** that you have to work full-time.”

“I looked after her on a more permanent basis. In 2019 she had a breakdown and then hasn't really recovered, and it's a tough gig. (I'm also) looking after her son, who's just turned 18, and **trying to work full-time**. We also have a charity together, which feeds the homeless on a Tuesday night, which is kind of like my soul food. It's my break.”

INSIGHT 3:

Administrative burden (red tape) affecting carers

Carers are the front line of supporting those in society who cannot support themselves. Carers feel the pressure of their caring responsibilities extensively - whether it is doing personal care or providing other support.

Reducing the administrative burden (red tape) on carers including assistance registering for NDIS or My Aged Care is vital to support carers and their care recipient getting the right access to the services they need.

Interviewees said that when caring for someone who's condition is declining, it is important that service providers take steps to ensure carers are not burdened with new administrative requirements each time they need to register or renew a service.

“...you're managing all the allied health people, everybody that you deal with, they all come to me for questions. I give direction. I tell them what to do. I tell them what not to do. I have to educate them about dementia, all those things, because you engage service providers where the training is not great. The quality's not great. People are not ready to really, I think there's a lot of training is required.”

“We've engaged support workers through the NDIS, **honestly, managing the NDIS is a full-time job.**”

INSIGHT 4:

Ability of system to respond to changing carer needs

Carers said that their difficulty navigating support systems has a detrimental impact on themselves and care recipient, in particular, when planning for future care support needs.

The level of support needs to reflect the needs of both carer and care recipient. Requirements can change both quickly, and over time, each of these changes creates an administrative burden on the carer.

If we expect carers to continue to perform caring duties to a certain standard, we must make it easy for carers to access support services that they need, when they need them.

One Interviewee identified having a supportive partner as crucial in helping them navigate and sharing their caring responsibilities. Whereas, another identified their only respite was via a hospital stay or use of residential facilities.

“And the whole thing is very tiring because you think about caring as being looking after the person, but in fact, what you're doing is **looking after the world around them** in a much bigger way.”

“Partner’s health goes downhill all-of-a-sudden and things aren't real good. But so far, I've been very lucky.”

“So far we haven't gotten any aged care support. I've managed to do everything around the house myself. We haven't had to use the healthcare support or anything like that so far. But I do most of the driving to appointments and things like that. He drives himself, but only he goes to a couple of the Vietnam Veterans coffee groups. Well, he goes there on his own, but everything else, yes, **I drive to all his medical appointments** and everything like that.”

INSIGHT 5:

Inadequate access to service providers and respite

An interviewee made the point that caring is a full-time job even if it is described as only “part time.” Whilst time invested in caregiving may vary, the emotional investment and potential need to provide additional ad hoc care, has an impact on carers 24/7.

Respite offers carers an opportunity to recharge. Flexible respite options allow the carer to choose respite options that work best for their situation – whether its short-term regular respite or an opportunity for a longer break.

Carers from marginalised groups and carers who are geographically isolated have increased pressures as a carer with less access to paid service provider, informal support networks or respite. It is important to ensure these cohorts have equal and equitable access to respite.

“In the country you are on your own. If you can't work a computer, you've had it.”

“There is no such thing as respite. You either go into hospital because you are ill or a type of aged care facility that bangs on about having respite. And you go in there providing you can shower yourself, dress yourself, feed yourself, take yourself to the dining room and participate in other things.”

“felt like nobody was actually going to help until a crisis happened “

“You don't know when you will be needed as a carer. Right now, I'm going well. I expect others, especially the government, to recognise the pressure and randomness that carers must live with.”

SECTION THREE

WHAT WORKS?

INSIGHT 6:

Government/service providers engaging with carers

To ensure the longevity of the care system, carers want the government to assist carers by reducing their administrative burden, being more agile in responding to changing carer needs and in assisting carers to predict and secure future care.

Leveraging the lived experience of both carers and those being cared for, is an essential approach to designing supports. Ensuring adequate government support is necessary to avoid carers being forced to make impossible choices for themselves and their care recipient.

Ensuring adequate training and compliance activities for service providers is vital to reducing carers' administrative and emotional burden. Quality service provision must include emotional intelligence and empathy training.

“So I think it's very important that those in the care system understand that very often we focus a lot of attention on the person who's described as needing the care, but the journey of that person to become in need of care very often **brings a bruises on the carer and others involved.**”

“So a service provider and their staff really need to focus on building human interaction skills, not just the practical skills, but **empathy, feelings, patience, kindness.** They need to promote developing those in their staff so they can interact with people regularly like the police. They also need to boost their training to recognise how to handle people with mental health challenges.”

INSIGHT 7:

The human rights of respite care

Respite care has traditionally been viewed as a holiday or the provision of in-home support services rather than a Human Right, 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).

Caring is a constrained choice and frequently reduces the carer's ability to maintain community and social connection, and manage their own self-care. Respite care enables a carer to have equal rights and opportunities to participate within their community and provides an opportunity for the carer to recharge from the constrained choice of caring.

Flexible respite options enables carers to perform their (non caring daily duties and provides opportunity for them to participate in social activities. This is valued by carers and can result in better carer outcomes and wellbeing. One interviewee highlighted that respite enables them to provide long term care and prevent burnout.

"I go to a weight loss club at 8.30am Wednesday, and I went to that this morning. I left here at 8:30 am and he was still in bed, and he told me he got up about 9:30 am and then I got home at midday. But it's a good group, even though it's a weight loss group, it's more like **we all support one another**, so I want to keep going to that each week."

"I've done about 13, 14 years at a church opportunity shop, and I absolutely loved it, but **I had to give it away** because I didn't like X being on his own. We were going to work from 10 till 3 pm."

"It's just **been on the go all the time**. I haven't had time to really do anything for myself. We just yesterday had made an appointment for X to go to a physio because the neurologist said there's not a lot they can do for his Parkinson's."

INSIGHT 8:

Better supported self-care for carers

Carer self-care is difficult to maintain due to the time commitment that carers need to invest in their role. As one Interviewee noted, when a carer's bandwidth is full, it is the self-care that stops, not the caring.

Allowing carers opportunities to exercise, volunteer or have a haircut, provides an outlet that helps carers cope, feel refreshed and revitalised and maintain social connections. Ensuring adequate mental and physical health supports and the wellbeing of the carer, extends the longevity of the care economy.

Government can support this by reducing red tape, being agile, ensuring high quality and empathetic service providers, and, recognising and funding respite care.

Some interviewees identified the benefits of informal care networks. Further awareness of carer impacts and ways of supporting informal associations would enhance this kind of organic support.

“But the carers don't necessarily have the time to go and do all that research on what they might need, so they need **someone to help them navigate** all that stuff.”

“So, I look after X getting some services in from Y, and that's helping. So, he's getting a couple of hours, twice a week, we'd have somebody come in and **I go and do aerobics.**”

“One of the things that's been really good with my husband is that he's been very **open about his diagnosis** from the beginning. He's wanted all our friends to know, wanted everybody to know. And that's made it a lot easier for me.”

INSIGHT 9:

Geographical equality

Rural, regional and remote locations where carers live and work present even greater challenges than those in suburbs or metropolitan areas mainly because of isolation and difficulties accessing service providers.

Communities without (or with limited) access to service providers often rely on informal networks that may not have the level of knowledge, expertise or understanding, that paid providers have. Additionally, informal carer support (regardless of location) is not always available when required. Opportunities to identify, educate and support informal carers would assist in supporting the care economy.

As noted by one Interviewee, some carers do not want to engage informal networks due to privacy or fear of perceived community perceptions.

Regardless of access to informal networks, all carers are entitled to formal care and alternate delivery methods should be identified to facilitate this where location is a barrier to delivery.

“There are people like me that are the key people who have been there for quite a long time, but conduit, you see, some of the communities that don't have that one person or the two people or three people that have been there for a long time, they do miss out on a lot of things.”

“Sometimes, the support, a person doesn't want to sign up as their carer with Centrelink because **everyone knows everyone else's business in a small town**, everyone knows that they're registered as that carer with Centrelink, they're getting the carers money and that now they are the designated carer.”

APPENDIX I

KNOWN ISSUES CARERS ACROSS AUSTRALIA MOST REGULARLY RAISE

ISSUE	KEY CHALLENGES
FINANCIAL IMPACTS	Carers experience significant financial stress/distress – both in meeting the immediate costs of caring, and longer-term financial impacts.
MENTAL HEALTH AND WELLBEING	Data from the national Carer Wellbeing Survey shows that carers are reporting falling levels of mental health and wellbeing.
CARER EDUCATION AND CARER EMPLOYMENT	Carers report challenges in completing study and/or participating in paid employment.
RECOGNITION AND INCLUSION	Carers often feel like they are overlooked, and their experience is not understood or valued.
FINDING OUT WHAT SUPPORTS ARE AVAILABLE TO THEM	Many carers tell us that they were or are unaware that support is available to them. Finding what is out there can be haphazard and sometimes is only discovered after years of delay.
NAVIGATING COMPLEX SYSTEMS	Carers tell us it’s increasingly complex to figure out how to access support, both for themselves and for the people they care for.
FINDING THE SUPPORT THEY NEED	Carers tell us that, even when support services are broadly available, they are not available in their location, or they do not offer the kind of support they need.
INCLUSION IN HEALTH, AGED CARE, NDIS AND OTHER SYSTEMS	Carers struggle to be regularly included in key planning meetings for those they care for. They also struggle to be included in opportunities to engage with broader system design and review activities, even though they have deep and direct knowledge.
ACCESS TO RESPITE	Carers need a break – but often struggle to find respite that suits them and others in their care relationship.

APPENDIX II

SURVEY RESPONSES

Redacted

Appendix II: Survey Responses Redacted



Participant no.	Age	State or Territory	Metro, Regional, or Remote	Age became carer?	Live with the person / people you care for?	Hours of care/Week	Currently employed? What type?	Who do you care for, and why do you provide care? (e.g. mental health, substance abuse, disability, chronic illness, degenerative illness etc.)
1	67	NSW	Metro	50	Yes	50+ hours per week	Not currently employed	Son CPTSD
2	78	VIC	Metro	70yrs	Yes	50+ hours per week	Not currently employed	Husband mental health Disability
3	44	NT	Remote	23	Yes	50+ hours per week	Employed, Full Time	Husband; disability - T10 -12 paraplegia; Son - ADHD
4	73	VIC	Metro	61	No	50+ hours per week	Not currently employed	My late wife, who died from pancreatic cancer.
5	70	SA	Regional	65	Yes	50+ hours per week	Employed, Part Time	Husband - Alzheimer's disease, reduced mobility
6	48	WA	Metro	39	Yes	50+ hours per week	Employed, Full Time	My wife - MH, Chronic illness
7	65	WA	Metro	49	No	20-49 hours per week	Employed, Casual	Mother - dementia
8	did not provide survey responses							
9	did not provide survey responses							

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