

# Carers Victoria submission to the National Carers Strategy consultation process, September 2024

Carers Victoria welcomes the opportunity to provide this submission to the National Carer Strategy Discussion Paper and notes that as a member of the National Carers Network, it also supports the submission made by Carers Australia.

Carers Victoria operates as both a provider of support to carers and an advocate for unpaid carers across the state. With over 30 years' experience, each year we engage with thousands of Victorian carers through a wide range of interactions. This includes:

- Provision of expert information and advice to carers,
- Delivering and connecting them to government funded respite opportunities,
- Delivering a mix of events, education and other supports for carers; and
- Conducting surveys and focus groups to shape our efforts to enhance the overall understanding of, and access to assistance for, unpaid carers.

This submission to the National Carer Strategy draws upon that extensive experience and connection, sharing some of the key points carers have told us are working and not working across the current system. It tells the story of a diverse group of people in care relationships<sup>1</sup> - a significant portion of whom are in multiple care relationships - who are challenged in finding timely, easy to access information and support that meets their needs and balancing the financial, health and emotional impacts of those relationships.

From our unique perspective, Carers Victoria observes that there is a need to consider ways of actively connecting carers to support early in their care relationships, so they can be equipped with the knowledge and skills that will enable them to maintain their own health, wellbeing and identify - and that there are better ways of them accessing succinct, tailored advice and ready access to support.

So many carers are time poor but tell us that current arrangements often require them to complete time-consuming assessments then wait weeks for basic assistance, much of which is one-off or episodic (unlike their care relationships).

This submission highlights where there are opportunities for national strategies, interventions and system modifications to build on what's working, and tackle what's not, so that carers can get what they need, when they need it, to maintain their own health, wellbeing and identity and manage the demands of their caring role.

Critically, we recognise that a systems approach is needed to leverage existing social infrastructure to enhance local responses, support earlier intervention approaches to carer assistance, embed carers across the health, disability, aged care, mental health and other service sectors, and enhance the assistance available to carers who may be struggling.

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<sup>1</sup> The Carers Australia submission speaks to the diversity of carers -in terms of their own identities, their demographics and their lives as well as the diversity of their care relationships.

We have also heard consistently from carers that more community education and awareness of their roles is needed to better support them in the important work they do in caring for a family member, friend or other person in the community.

The new National Carer Strategy provides a unique opportunity to shine a light on the invaluable contribution of all unpaid carers across our communities and to embed accountability mechanisms that ensure all Australian Government funded entities are alive to, and doing their bit, to raise awareness about, and inclusion of, carers across the range of levers at their disposal - from service and policy design and review through to employment.

Comments addressing the consultation process questions are set out below. These comments are informed by our analysis of emerging trends drawing on data and insights from carers. Key data relevant to Victorian carers is provided throughout this submission to provide additional context.

## Principles

### *Q1. What principles do you think should be in a National Carer Strategy?*

Carers have told us that it is critical that lived experience is at the heart of all decision-making concerning strategies to support their caring roles. Codesign and co-production are central tenets to this.

Fundamentally, principles which underpin the collective work of governments and others to deliver and enhance services and supports to carers must be centred in lived experience, recognition and respect.

Carers Victoria encourages the Australian Government to consider principles such as those set out in Scotland's Equal Partners in Care principles, which reflect this contemporary approach:

- *Carers are identified*
- *Carers are recognised and valued as equal partners in care*
- *Carers are free from disadvantages or discrimination related to their caring role*
- *Carers are fully engaged in the planning and shaping of services<sup>2</sup>*
- *Carers are enabled to have a life outside of caring*
- *Carers are supported and empowered to manage their caring role.*

Carers Victoria supports the recommendation of the House of Representatives Standing Committee on Social Policy and Legal Affairs regarding the need for robust action plans, outcomes measurement and reporting and evaluation frameworks in the new National Carer Strategy<sup>3</sup> as it is through practical actions that carers will experience genuine change.

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<sup>2</sup> Carers Victoria notes the importance of this principle also including active involvement by carers in review and improvement activities.

<sup>3</sup> House of Representatives Standing Committee on Social Policy and Legal Affairs' Report of the Inquiry into the recognition of unpaid carers 2024

Another key principle for inclusion in the National Carer Strategy should be that the diversity of carers, their lived and living experiences and their care relationships are reflected in both the Strategy and national actions arising from it.

## Caring role

**Q2 What does your caring role involve or look like for you?**

*Are you a Primary Carer? And do you have secondary assistance, such as extended family also providing some care support?*

In considering the roles undertaken by carers, it is important to firstly understand the breadth and diversity of the carer experience.

The latest national data shows that the number and proportion of carers are growing, as is the diversity of the carer population – as the Victorian Carer Snapshot opposite illustrates.

Importantly, it highlights some important data regarding what caring roles look like:

- The majority of people who are primary carers consider themselves the sole primary carer, suggesting that the weight of the care responsibilities for this group primarily falls to a sole person
- The lower levels of participation in paid employment by carers, which can at least in part be attributed to the significant proportions of carers delivering over 40 hours of unpaid care a week and/or in more than one care relationships
- Carers experience high levels of disability themselves

**Q3 What additional supports and/or skills do you need or would like to develop to assist or support you in your caring role?**

Across Victoria, carers have told Carers Victoria about a range of areas where their needs are not being met and where additional supports are needed. Some of these relate to the way in which existing programs are delivered or the available supply; others related to gaps in broader system design:

In relation to existing offers, some of the gaps identified by carers we have spoken to include:

- Timely, succinct access to expert advice and navigation assistance

## Snapshot of Victorian Carers

*Available data suggests that in 2022 there were at least 758,500 carers in Victoria of whom 38% were primary carers<sup>1</sup> (30% ↑ from 2018). Of this group,*

- 85% were sole primary carer
- Women were more than twice as likely to be primary carers.
- 45% were living with a disability (37% ↑ from 2018).
- 32% spend 40+ hours caring, up from 22% in 2018. <sup>1</sup>

*Of Victoria's non-primary carer population:*

- 54% are women and 46% are men (noting a small increase of male carers from 2018).
- 13% of carers are under the age of 24 (3% of people aged under 14);
- 28% are aged between 25 and 44 years; 34% are aged between 45 and 64 years and 25% are aged over 65 years. .

*Of all carers in Victoria:*

- 39% report living with a disability
- 54% participate in the paid workforce
- 52% from income from employment, 25% receive government pensions and allowances.
- 21% of Victorian carers are born in a non- Main English Speaking Country (SDAC)
- 15-30% care for more than one person

- Greater ability to flexibly respond to carer needs so that more immediate, practical relief can be provided. For example, sometimes what carers most need is access to fuel vouchers or other material aid that allow them to fulfil their caring role and the absence of means to meet those costs is a significant stressor.
- Opportunities for social connection and funded activities are highly valued, particularly catered events.
- Local access to assistance in rural and regional areas, particularly ways of supporting carers to connect face to face locally without extensive travel times and associated costs.

Some of the more system-wide gaps that carers have identified include:

- Longer term support for carers with complex and/or multiple care relationships
- Access to in-home respite, particularly where there are specific needs - where someone in a care relationship has complex or intensive needs, and/or requires bilingual workers, there can be significant delays in accessing suitable in-home respite provision OR there is time required to build rapport and safety with the client before in home respite can be taken (which funding models may not accommodate). Note Carers Victoria has raised this as an issue for federal consideration.
- After hours support - where a carer combines care responsibilities with employment or study, there may be few opportunities for them to access respite during traditional business hours, but current funding models make it challenging to deliver after hours assistance.

There also remains a strong need to better meet the needs of carers who experience barriers to access, or are in a care relationship with one or more people who have needs that are not currently met through 'mainstream' services. A recent example of this that has been raised with Carers Victoria relates to carers who are deaf, or are in care relationships with people who are deaf, who have relayed significant challenges in for example accessing emergency respite from a service that can provide a AUSLAN worker.

Maintaining a national register of organisations that have this capacity, ensuring federally funded providers have a minimal level of capacity to access such services for carers when needed, providing information in AUSLAN for Australian carers, and other practical measures would also be positive steps towards addressing barriers to access. Similar strategies should be considered for culturally and linguistically diverse groups.

## Support for Carers

**Q4** Do you know what services are available to support you in your caring role?

*a. Do you know how to find and access carer supports?*

*b. Have you used any carer supports or services in the past?*

One of the things carers most frequently tell Carers Victoria is that it is difficult to understand where to begin and then find details of what services are available and how to find them.

For example, in focus groups conducted by Carers Victoria with over 300 carers over the past two years, this has been one of the three most commonly reported challenges.

There are a range of things that carers have been telling us about this challenge. Some report being deterred by the time between making contact and being able to access a funded service, while others have reported the time taken to complete initial assessment processes as a barrier to utilising existing systems such as the Carer Gateway.

In response to this gap in the system, Carers Victoria has funded the establishment of a Statewide Carer Advisory Line which aims to give carers immediate access to practical information that can help them connect more quickly to available support. This service was established in 2021 and in the past two financial years, almost 10,000 calls have been taken by this service despite minimal promotion - a very practical example of the need for timely, expert and succinct assistance. Ideally, this would be funded as a national service that could be run by carer organisations to ensure strong connection to local supports for carers.

Another element of the current arrangements that is challenging is that carers often express frustration at having to tell their story multiple times and/or justify that they are indeed in a care relationship.

Thinking about strategies that could make it simpler and quicker for carers to establish their role would be practical way of tackling this. The Australian Government is uniquely positioned to lead improvements in this area in its role as system steward for key pathways and supports such as the Carer Gateway, My Aged Care, Centrelink, Services Australia and the National Disability Insurance Scheme.

**Q5** *If you have accessed these services, what has worked for you or where have you experienced challenges?*

Data Carers Victoria has collected from people who have accessed a mix of its services and assistance shows that:

- Carers participating in group activities that were focused on increasing social connection reported a high level of connection with other carers over two thirds reported they were able to more effectively focus on their own health and wellbeing after the activity

*"We finally found [some support] after 18 months of not knowing anything about it. Again, it's the lack of information out there. Even GPs aren't aware of the services that are available"*

**Carer participating in focus group**

- Activities more focused on caring for oneself were valued for the opportunity they provided carers to step away from their day-to-day duties and provide space for themselves and their own wellbeing.
- Where practical supports could be provided, these were highly valued by carers, many of whom reported significant financial stress or financial distress.

There are however broader challenges across the sector. For example, of the Victorian carers who responded to the 2023 Carer Wellbeing Survey:

- Approximately 50% reported receiving no assistance to help them in their care role.
- Only 13% reported accessing a carer assessment and planning service, although 46% reported that they would like to access a (funded) carer assessment and planning service.
- Less than a third of carers who accessed a range of supports reported high satisfaction with those services.
- Long waiting lists to local services, poor availability of high-quality services and complicated application processes were identified as common barriers to access.
- 36% reported that another barrier was the care recipient declining support, such as respite, underscoring the need to develop flexible models of support which meet the needs of care recipients.

## Respite

**Q6** We are aware that some carers feel they cannot leave their loved one with others due to the complexity of the care required. What has prevented you from accessing respite and what additional support might relieve your hesitancy to access respite in the future?

Content in previous sections of this submission have spoken to the challenges carers report where respite is needed but a longer lead time to build familiarity and trust is required, or there is specific language or other skills needed for it to be successful.

It is worth reiterating that these are often more marked in rural and regional areas, exacerbating the additional challenges that rural and regional carers may face in accessing services, incurring the additional time and cost of travel in doing so, and/or being more isolated.

On current data, there will be more than one million carers in Victoria by 2025, a significant number of them assisting the expanding population of older Victorians aged 75+.

Expanding investment and access to respite is needed as a priority to start building future capacity and address current gaps. Supporting carers sooner within their local communities is important to improve carer health and wellbeing, and assist in making care relationships more sustainable.

*I was told by an NDIS planner once that I had no right to have a holiday, because I said I just want some money for some respite. "well we send each of your kids off on respite but you don't get any respite". So, I could have one go at a time and I'd still have the rest, but (they said) you don't qualify.*

**Carer participating in focus group**

## Q7 What do appropriate alternative care arrangements look like for you?

Carers have told us that respite is one of the key supports that helps carers to maintain their own health and wellbeing to support them in their caring roles.

However, access to high quality, accessible and family-centered options can be limited, particularly in rural and regional locations and, as previously mentioned, people in care relationships where one or more have particular needs often need funded respite that gives time for trusted relationships to grow before the respite itself is taken. There is also a need for respite options where people in care relationships have particular language or other needs.

*I've actually tried to get services that understand dementia during the week, it's for my wife and because she's familiar and comfortable with them, the respite is I leave home and I go away. She stays at home, her own environment, she knows that room, she knows as soon as that somebody comes through the door, she knows the face.*

**Carer participating in focus group**

One of the issues raised with us has been the absence of choice in respite providers when that support is sought through Australian Government funded services.

The recent report of the Standing Committee on Social Policy and Legal Affairs' Inquiry into the recognition of unpaid carers examined this issue in some detail, recommending that the Australian Government undertake urgent work with the carer sector to identify capacity building for high-quality respite care options that are appropriate for a diverse range of carers and the people they care for, including those that require complex care.

Carers Victoria is keen to work with governments, other sector partners and carers to strengthen respite care and recommends this is a key priority action under the new National Carer Strategy.

This work should explore innovative respite models that meet individual carer's needs and preferences, for example respite models that don't rely on face-to-face contact, for those carers who prefer not to leave the home in all cases.

## Employment and Education

### Q8 What carer-inclusive practices could benefit your workplace or education institution?

### Q9 What types of assistance are available to you in your education setting, or in the workplace that you find helpful?

Through a range of activities, carers have told Carers Victoria of a range of carer inclusive practices that would benefit them in workplaces and education settings, in particular highlighting:

- Easy access to flexible arrangements, often at short notice. For example, working remotely, flexibility with deadlines for learning tasks.



- Well documented, and up to date policies that can be accessed by all employees (including managers) and education staff that outline both carer inclusive arrangements and mandatory obligations.

#### Additional time for learning tasks

- Flexible arrangements for exams.
- Temporary modifications to duties that recognise moments of cognitive overload and allow for modified duties (for example, repetitive or simple administrative duties, when the impact of carer responsibilities is significant).

*Even though I am in a work environment that is flexible, I am afraid to say that my daughter has a disability and a rare syndrome because people might think I would be required to use more sick leave or be unreliable or take more time off or just feel sorry for me and see me differently*

**Carer participating in focus group**

#### Q10 How can we best support carers to stay in or re-enter the workforce or education system?

From its considerable experience in working with carers seeking to re-enter or remain in paid employment or study, Carers Victoria knows that carers are best supported to stay in or re-enter workforce or education setting when those supports are a mix of:

- Practical job/study readiness preparation, especially after significant periods of being inactive in work or education settings including how to approach employers /educators for flexible work/study arrangements.
- Job / study application assistance that consider the nuances and shifts of contemporary practice over time and recognition that things change quickly.
- Practical assistance to identify transferable skills developed in a carer role and to build key competencies when these are absent or diminished.
- Tailored supports to meet their specific needs, in recognition that the unique nature of each care's circumstances means the need for employment support (both pre and post-employment) varies considerably.

There are also opportunities to consider innovative strategies such as income smoothing to moderate the impacts of financial shocks/insecurity that can arise when caring responsibilities impact employment.

## Priorities

#### Q11 What are the top three challenges you face as a carer?

Carers Victoria has undertaken a number of structured consultations with carers across the State, as well as informal discussions with individual carers who contact us for information and advice. Through engagement with thousands of carers, a series of challenges are consistently identified:

- Financial insecurity, with repeated calls for there to be increased financial support for carers including allowances, subsidies and concessions,
- Personal health and wellbeing, particularly the challenges of accessing timely, funded mental health and emotional support services and/or tailored carer education that enhances knowledge and capability,

- Social isolation - and lack of time (and resources) to remedy that,
- Finding suitable (and accessible) support as a carer, particularly in relation to assistance such as in-home care and transport assistance, with many carers noting that while these can be critical they are not consistently supplied,
- Juggling care roles with education and/or employment, and concerns about workforce inflexibility,
- Accessing services - particularly for those who experience living in regional or rural areas or social isolation, and
- Recognition, inclusion and support.

*We had very little support at the start because we did not know where to go. We've only slowly got to a point now where we've got half an idea.*

**Carer participating in focus group**

While all the above are critical challenges, the three that appear to be most pressing for the majority of carers with whom Carers Victoria has engaged over the past 12 months relate to:

- Financial security,
- Accessing suitable, timely, funded supports and services, and
- Recognition, inclusion and support<sup>4</sup>.

### **Q12 What do you consider are the biggest opportunities to improve the lives of carers and the people they are supporting?**

With financial impacts, simpler ways of navigating to assistance, more flexible supports and carer health and wellbeing are some the biggest factors impacting carers, a National Strategy provides a unique opportunity to tackle all three - and more.

Across multiple areas, achieving consistency across government funded programs would make a big, and practical, improvement to the lives of carers - a significant shift from current arrangements where carers tell us waiting times and the menu of supports available vary between locations.

Reimagining the financial support available to carers whose caring role impedes their opportunities for economic participation is essential. There are a few components to this:

- Income assistance/supplementation that recognises the opportunity cost of providing unpaid care, provides a fair and reasonable level of financial support and moves away from considering it as a welfare payment but rather a recognition of the work done.
- Finding a smart solution to minimise the compounding effects of the caring role on carer retirement savings is also required, recognising that finding ways of topping up superannuation for example has the longer-term benefit of reducing reliance on aged pensions, etc.
- Providing greater flexibility in what supports are funded, recognising that sometimes what carers need is assistance in managing the immediate financial costs of their caring role. For example, very practical options such as free grocery home delivery services for all carers receiving the Carer Allowance would free carers' time for other purposes, whether that is attending to their own health and wellbeing or creating additional time for things like preparing meals for everyone in their care and family relationships.

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<sup>4</sup> Which in turn is a critical enabler for supporting carers in employment and education and to maintain personal health and wellbeing.

- Some carers have also advocated for a national Carer Card that both allows for easy identification of someone in a care role and provides meaningful benefits from fuel and utility discounts through to discounts on health and wellbeing supports (from gym memberships and personal training through to nutrition and dietetic consultations).

More flexible and creative supports is an area where carers have identified substantial opportunities for improvement, and a range of these have been discussed earlier. Carers themselves have given us other examples of how and what they may need as carer support needs to be tailored to their circumstances - recognising that these will change over time - and include capacity to accommodate very practical assistance. For example:

- One carer was satisfied with help to cook batch meals so her family could be provided for when she was away, and another was seeking a robot vacuum which would allow them to maintain a healthy environment when they themselves experienced significant pain.
- Flexibility in service provision - in the type of service or support, and the level of support available.<sup>5</sup>

There are substantial opportunities to deliver improvements for carers by designing systems, processes and supports that are genuinely carer-centric and simplify ways of navigating assistance. These should be supported by easy access to national information and databases that can make it easier for carers.

As recommended in the Final Report of the Inquiry into the recognition of unpaid carers, the National Carers Strategy should prioritise carer health and wellbeing.

We note that the health and wellbeing of carers is significantly lower than Australians who are not in care roles; this includes rates of psychological distress, social isolation and physical health (see text box).

Carers Victoria has achieved promising results from programs that support carers to better manage the mental health and emotional impacts of their caring role, and these kinds of programs alongside carer education that provides carers with information about services, supports and health and wellbeing strategies can have a significant impact on the sustainability of their role.

### **The mental health and wellbeing of carers is deteriorating**

In 2023:

- 50% of Australian carers reported their health as fair or poor. Only 20% reported their health as excellent or very good. These numbers are reversed for Australians not in care roles.
- 26% of Victorians reported high levels of psychological distress compared to 23% of adult Australians in the first half of 2023 and 31% of carers were experiencing these levels of distress.

All carers are twice as likely to report high levels of loneliness compared to Australians not in care roles (39% to 19%), with more Victorian carers reporting this in 2023 than in 2022.

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<sup>5</sup> For example, many carers have highlighted the need for there to be varied 'dosages' of support, for example more intensive support at times of transition or crisis when there are often significant changes to be navigated in an environment that is stressful for both carers and the people they care for.

Programs such as Healthy Mothers, Healthy Families include robust, evidence-based activities and strategies which demonstrates the positive impact that tailored education can achieve.

Developing Carer Wellbeing Plans alongside the plans developed for clients of the aged care, mental health and disabilities systems should also be considered as a way of ensuring that all members of the care relationships have appropriate support and that people entering or maintaining care relationships have access to strategies and supports for their physical, emotional and nutritional needs including referral to assistance where needed.

## Peer Support

**Q13** Have you accessed peer supports? What did you find beneficial, or can you identify areas for improvement?

Some carers tell us that they really value peer supports for the opportunities they provide to share stories, learn local 'tips and tricks' that can assist them in their caring role, and help them counter social isolation and loneliness. In Victoria, a diversity of peer support groups provides very local connections to others who 'get what it's like' - and by being local, can offer a point of support for carers who may otherwise have to incur significant time and expense to access face to face support.

Victorian carers have told us that they can see real benefit in carer peer support pathways whereby carers who are at different points in their caring journey can connect with the experience and knowledge of others who have traversed similar pathways. They have also told us the importance of valuing Carer Peer Support Leaders and ensuring they can access appropriate training and resources to deliver peer support programs.

There are, however, other segments of the carer population who don't want that kind of connection for myriad reasons and thus it is important a range of individual and group offers (the latter including peer supports) be available.

The data also speaks to that diversity, with the results of the 2023 Carer Wellbeing Survey suggesting over 68% of Victorian respondents had not accessed peer support in the 12 months prior, consistent with results for some years at both a state and national level. However, of those Victorians who had accessed peer support, 79% reported moderate to high satisfaction.

## All Carers

**Q14** How would you like to see your experiences reflected in the Strategy.

**Q15** If you belong to a diverse group, what opportunities do you see for the Strategy to improve access to supports and information in your community? (For example, have you identified a gap or challenge in receiving support and/or information for your particular diverse community and what could Government consider improving the issue).

**Q16** What are some priorities that might assist or improve the experience of carers within your community?

As noted elsewhere in this submission, understanding and responding to the diverse needs of carers is a critical enabler of improved outcomes for all carers.

Carers Victoria has found the use of the construct of supporting care relationships to be particularly valuable, as it provides flexibility to accommodate the diversity of care relationships, as well as the diversity of people in those relationships. This emphasis on care relationships can assist programmatic and policy responses to reach individuals who may not identify with the term 'carer', due to cultural or social expectations of care provision within family or community settings.

Research undertaken by the Multicultural Centre for Women's Health notes cross-cultural understandings of 'caring' vary significantly and can involve obligations to undertake significant and possibly onerous care roles. This is likely to be a factor in low carer self-identification within immigrant and refugee families and uptake in carer-centered supports.

Similarly, people reflect very different understandings of the care role and the term 'carer' itself. As noted in the 2017 'Dealing with it Myself' report, "there is no direct equivalent of the term 'carer' in many languages."<sup>6</sup> Consultations undertaken by Carers Victoria in 2019 show that these beliefs and barriers are not exclusive to culturally and linguistically diverse carers but are also present for carers from Australia's First Nations, young carers, and carers who identify as LGBTIQ+. Carers from diverse communities such as these are more likely to face barriers to accessing information and services - particularly in seeking out culturally specific or targeted programs - compared with those who do not belong to a diverse community. Common themes that relate to the needs of specific cohorts such as young carers, First Nations carers, LGBTIQ+ carers, or culturally and linguistically diverse carers, include:

- A lack of self-identification with the term 'carer',
- A lack of carer support programs specifically designed response to the needs of these cohorts,
- Issues with stigma, including the common perception that accessing respite means the carer has 'failed' in their care role,
- A preference for meeting individual needs, and
- Concerns around allowing unknown service provider staff into the home, related to cultural safety.

In consultations undertaken to inform the 2024 National Carer Survey, many First Nations carers reported that yarning and learning from Elders, sustaining and sharing culture and traditional knowledge, and preservation of language, values and traditional practices were important to them. Carers reported that services that met these needs and prioritised cultural safety positively affected their experience and helped them feel listened to, valued and empowered.

Similarly, First Nations carers emphasised the importance of services understanding the ongoing impacts of colonisation. It was important to carers that systems address the enduring racism and discrimination, and work to break down systemic barriers. Respondents expressed the need for services to support First Nations carers in a trauma-informed way, showing respect and empathy.

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<sup>6</sup> Aryal R. (2017) Dealing with it myself: Supporting Immigrant and Refugee Carers in Australia, Multicultural Centre for Women's Health: Melbourne, page 13.

A few First Nations respondents emphasised the importance not only of improving access to funded services on Country and closer to their home and family, but also of strengthening education, research, and innovations in Indigenous health, or enhancing health promotion practices through community support networks, more widely available psychological support, nutritional intervention, and the like.<sup>7</sup>

Carers, including young carers, have told us that it is critical to the improved engagement and outcomes of diverse carer groups that specific measures are taken to gain access to the full spectrum of carer perspectives, including through addressing cohort-specific barriers these carers may experience.

Key to addressing these barriers and improving engagement of diverse carer groups is ensuring carers with lived experience of challenges and barriers is actively sought out so that services and supports focus on solutions sought by these carers.

## Payments

**Q17 Do you have any views on how the assessment process for carer payments in the social security system is working?**

- a. Are there any ways we could make it easier for carers to demonstrate they are eligible for a payment?
- b. What barriers have you experienced in demonstrating your eligibility for a payment that we should be aware of?

For context, as at March 2024, there were approximately 74,725 Victorians receiving carer payment - roughly 10% of the estimated number of carers in the community.

At the same time, there were 168,800 Victorians in receipt of Carer Allowance. 50% of Victorian Carer Payment recipients are aged between 45 and 64 and 21% are aged over 65 years of age. 2.3% identify as First Nations carers despite the higher prevalence of caring in Indigenous communities.<sup>8</sup>

Application procedures to access the social security system have been reported by carers as inflexible and time consuming. Efforts to streamline and simplify the steps needed to access carer payments should be prioritised.

*I've got an adult son with treatment resistance paranoid schizophrenia, clinical depression and social anxiety. His drinking addiction has also caused a lot of problems over COVID. As soon as he goes into rehab, they tell me I'm no longer a carer. They cut my pension and I have to reapply for it.*

**Carer participating in focus group**

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<sup>7</sup> This data represents early insights from responses to the 2024 National Carer Survey based on analysis conducted by Carers NSW for the purpose of responding to the Discussion Paper. Official results based on the finalised dataset will be published in National Carers Week 2024.

<sup>8</sup> DSS Benefit and Payment Recipient Demographics - March 2024 Quarter

Some carers have told us that they can experience challenges at transition points in the lives of the person for whom they are caring, for example older family members moving into aged care, children turning 16 triggering a review of eligibility for support.

Some carers have raised with us their perception that the carer payment system is geared more towards care which involves support to the physical needs of care recipients rather than those who live with chronic conditions such as dementia, psychological distress, mental illness or neurodivergence - the carer story provides a practical example of how current system settings drive unnecessary complexity and administration.

The evidence required to apply for carer support can also be difficult to obtain and 'prove', which in turn exacerbates poor health and wellbeing for carers. Some carers have suggested greater education for GPs, psychiatrists and other physicians on the role undertaken by carers would be helpful to better inform them in preparing advice on eligibility for carer payments.

A recent change to rules regarding the number of hours carers could work, study or volunteer (100 hours spread over a month rather than 25 hours a week) whilst receiving Carer Payment has been positively received by carers.

## Other Services

Q18 Have you ever required emergency assistance or emergency support/s in your capacity as a carer?

a. Did you experience any barriers to accessing these emergency support/s due to your role as a carer?

b. Did the emergency support/s meet your and your care recipients' needs adequately (for example was there wheelchair access to emergency evacuation points; access quiet spaces for neurodiverse people?)

c. Would you like to share your experience?

The use of emergency respite by Victorian respondents of the Carer Wellbeing Survey was just 4% in 2023, with over two thirds reporting poor access to the service. 10% of Victorians reported they didn't receive it despite efforts to access.

As previously highlighted, access to emergency respite becomes particularly challenging in circumstances where one or more people in the care relationship have specific language or behavioral needs or, as the carer story opposite illustrates, if you have multiples care relationships. Rural and regional factors exacerbate these issues further.

*My biggest challenge is what would be called emergency respite. I care for two family members who both have multiple mental health and neurological illnesses, both are neurodivergent. I can have both of them having a seizure at the same time. So, everyone says 'take care of me' ...[but] if someone has a seizure, I don't get that opportunity. You know, the organisations all say emergency respite is available, but when you need someone in a rural area in the next 5 minutes and you don't have support workers....and you're going in an ambulance 45 minutes away and the other one needs someone to come. It's very challenging to actually get someone to come for the second person because its this distance and there's just not enough time.*

**Carer participating in focus group**

## Any other issues/comments

Carers Victoria is keen to see that carer diversity informs all actions arising from the Strategy, including targeted support for First Nations and culturally and linguistically diverse carers, and LGBTIQ+ carers.

Governance structures to support implementation of the National Carer Strategy are important to get right from the outset and Carers Victoria would be keen to see a Standing Carer Advisory Committee be established to oversee implementation and evaluation of the Strategy.

As noted earlier in our submission, the principles underpinning the Strategy should ensure that carers have a central role in actions delivered under the Strategy. Carers have repeatedly reported 'invisibility' within their local communities and the Strategy presents an opportunity to bring the carer experience to the fore through meaningful commitments to genuine partnership and co-design.

An example within Victoria of contemporary approaches to embedding the inclusion of lived experience in policy and program design and delivery is through the implementation of



recommendations of the Mental Health Royal Commission. The Mental Health and Wellbeing Act (2023) embeds the inclusion and representation of carers of people living with mental illness and/or psychological distress as separate but equal stakeholders to people living with mental illness and/or psychological distress. The legislation also specifies that people with lived experience of caring be employed to lead and shape the design, commissioning and delivery of services. Carers Victoria would be keen to see similar commitments applied to all carers under the new National Carer Strategy.