

# Care for Victorians Policy Platform

2022



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# ABOUT CARERS VICTORIA

Carers Victoria is a not-for-profit organisation that helps and promotes awareness of Victorians who are caring for someone who needs support due to disability, mental illness, an older person with health needs, or other significant health issues. People receiving care could be a parent, child, spouse/partner, grandparent, other relative or friend.

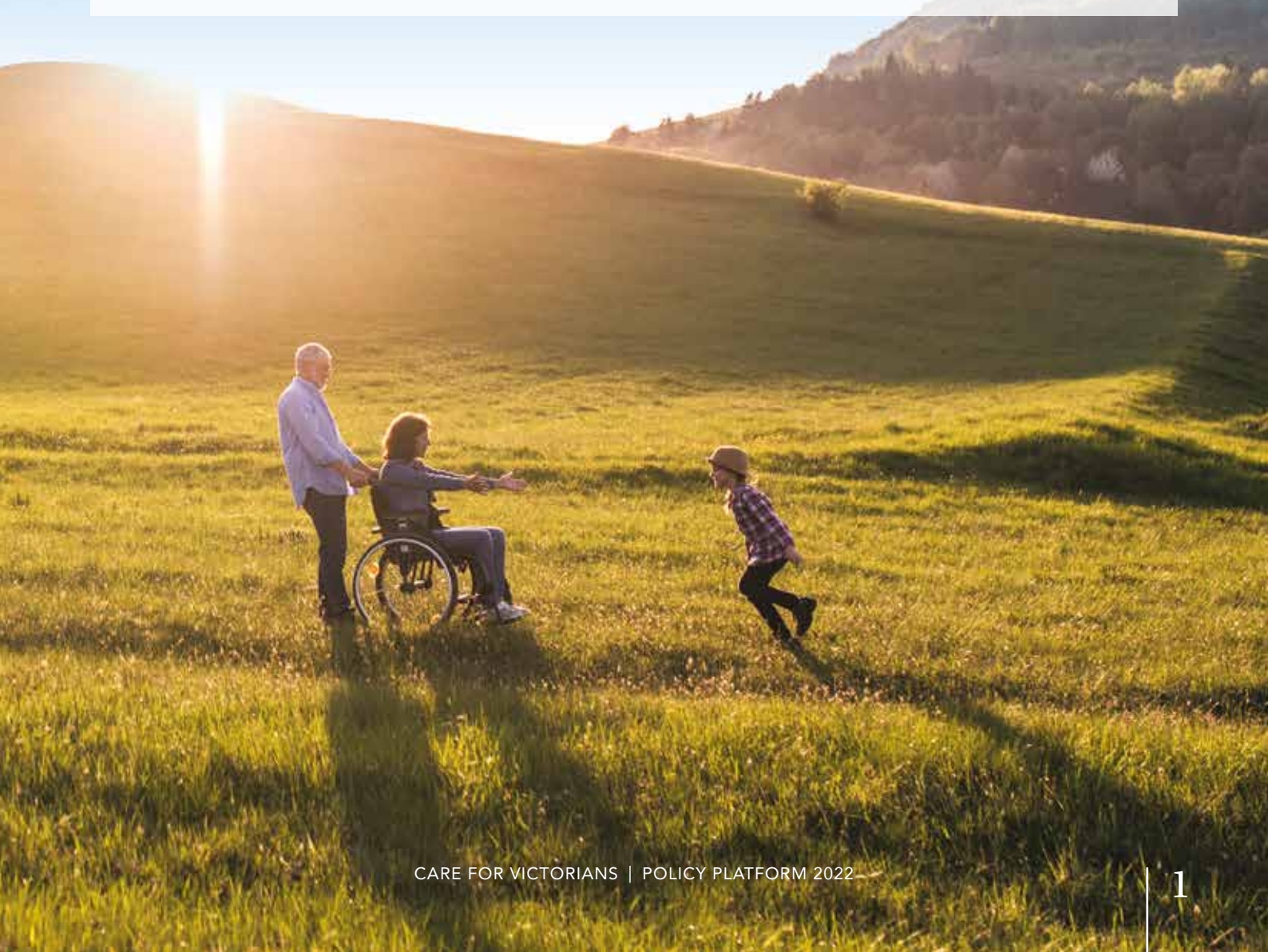
Our vision is an Australia that values and supports all carers, and we want to ensure that caring is a shared responsibility of family, community, and government.

As the state-wide peak body for all carers, we engage with carers and analyse research and evidence to understand current and emerging issues that may impact their caring role.

Alongside this we deliver support programs, provide information to and create connections between carers, and advocate for changes that can make carers' lives better.

We work with governments, service providers and a wide range of other organisations to shape policy and increase understanding of, and support for, carers to help make their lives better.

Over the past three years we have responded to almost 95,000 incoming telephone calls ranging from general enquires from the sector to situations requiring urgent and intensive support; and provided more than 97,000 support activities to nearly 13,000 carers.



# EXECUTIVE SUMMARY

Carers make a critical contribution not just to the lives and families of the people they care for, but to our broader community. It is estimated that the economic cost of the support provided by Victoria's carers is equivalent to **over \$19 billion every year**.

There are **over 700,000 Victorians in unpaid caring roles**, each of whom is providing care to one or more other Victorian, so supporting those care relationships is an area with major reach across our state.

Victorian carers have told us that having their role as a carer recognised and supported by service providers, employers and others is a key challenge. **Their caring role is complex, time consuming, and it's often confusing to navigate through systems** to access and secure what they, and the person they are caring for, need.

Carers talk about the negative impact that caring can have on their own health and wellbeing and the challenges of securing and sustaining employment or engaging in study. They sometimes note the loss of simply enjoying the freedom to do as they choose, which those who are not in care relationships often take for granted.

The COVID-19 pandemic has exacerbated these challenges for many carers, with results of a recent survey of over 1,100 carers indicating that:

- › **Most felt their mental health had worsened since the pandemic started**, with 76% reporting increased levels of loneliness (substantially above the 54% rate reported for the general public).
- › **Carers were providing more care, including more complex care** - over 80% of carers reported they spent more time in their care roles over the pandemic and over 50% were providing complex care that would usually be provided by trained professionals.
- › There were **substantial impacts on carer employment**, with 47% of respondents changed their employment arrangements to accommodate their care relationships during the pandemic, 12% resigning or retiring to do so. Of respondents, 9% wanted help finding paid employment.
- › **Carers were uneasy about re-engaging in a COVID normal environment**, with 72% saying they would self-impose restrictions on their activities.

To sustain carers into the future and ensure they can transition to COVID normal, there is a pressing need to progress action across five pillars. The table below summarises each of these, and priorities for action.

Pillar	Priorities for action
Support carer mental health and wellbeing	<ul style="list-style-type: none"> <li>› Fund dedicated Carer Mental Health and Wellbeing staff in at least 20% of Local Adult and Older Adult Mental Health and Wellbeing Services so that all carers can access timely mental health and wellbeing support.</li> </ul>
Simple and flexible supports for carers	<ul style="list-style-type: none"> <li>› Establish a state-wide carer advisory service that can help carers navigate complex systems.</li> <li>› Sustain and grow flexible funded support for carers so that 112,000 additional Victorians are receiving this support each year by 2026.</li> </ul>
Support carers in crisis	<ul style="list-style-type: none"> <li>› Establish a carer focussed crisis line through which carers can seek advice and support to respond to emergencies.</li> <li>› Embed specific consideration of the needs of carers into state-wide emergency planning and response activities.</li> <li>› Equip carers with practical resources to plan early for the future.</li> </ul>
Support more carers into employment and study	<ul style="list-style-type: none"> <li>› Ensure young carers are proactively supported to remain engaged in education and training.</li> <li>› Consolidate and recurrently fund local pathways and architecture to support carers into employment and training.</li> <li>› Support programs that encourage employers to recruit and retain carers.</li> <li>› The Victorian Public Service become a leader in carer employment, including the establishment of state-wide targets.</li> </ul>
Integrate carer expertise and input into key service systems	<ul style="list-style-type: none"> <li>› Recognise the role and expertise of carers in legislation governing health care, disability, mental health and other relevant areas.</li> <li>› Ensure carers are actively involved in government advisory structures to shape program design, implementation, and review.</li> <li>› Establish a program to support carers in taking up an active role across key service systems.</li> </ul>

Strong foundational work has commenced to implement the recommendations of the Mental Health Royal Commission, foundational investments in carer employment and training initiatives, and the Support for Carers program.

Building on the strong whole of Victorian Government platform provided by the *Victorian Carer Strategy*, and leveraging the expertise, resources and enthusiasm of Carers Victoria, its members, and partners, we can create a system that will sustain and empower carers as we transition to COVID normal and look to the future.

# INTRODUCTION

An estimated 1 in 9 Victorians care for someone who needs support due to disability, mental illness, an older person with health needs, or other significant health issues. People receiving care could be a parent, child, spouse/partner, grandparent, other relative or friend.

This is something that touches us all: all Victorians will, at any point in their lives, be a carer, need a carer and/or know a carer. With forecast changes to our population, it is likely that more of us will become carers in the future.

To rise to these challenges and support carers to sustain their contributions to our society and economy, we need to act now – particularly as Victoria seeks to rebuild in a new, COVID normal environment.

Our recent survey of over 1,100 carers showed that 80% of carers spent more time undertaking their caring role during the pandemic.

Carers are reporting to us that they are lonelier and are less satisfied with life, had to take on more of the clinical support that had been provided by trained professionals, still struggle to access key services like respite, and want help with things like securing flexible employment.

We need to ensure that carers are healthy and that care relationships are sustainable.

*Care for Victorians* is Carers Victoria's policy platform for the coming period, which sets out priority actions across five key pillars to start building towards that future:

1. Support carer mental health and wellbeing;
2. Simple and flexible supports for carers;
3. Support carers in crisis;
4. Support more carers into employment and study;
5. Integrate carer expertise and input into key service systems.



All Victorians will, at any point in their lives, be a carer, need a carer and/or know a carer. With forecast changes to our population, it is likely that more of us will become carers in the future.

# VICTORIA'S CARERS – THE CURRENT PICTURE

## Who are Victoria's carers?

Of the estimated 700,000 carers in Victoria, most carers are partners, however parents, children, grandparents, other relatives or friends also make significant contributions to the informal caring ecosystem.

People receiving care may have multiple care needs and often carers themselves have care needs. Carers are at least twice as likely as people without caring responsibilities to have a physical disability and are also more likely to experience mental health concerns.

A large concentration of carers live in Victoria's cities with around 25% living in regional areas and 5% in rural areas.

The supports carers provide vary substantially and will change over time. Typically, these may involve a combination of one or more of physical, social, and/or emotional support<sup>1</sup> in relation to areas such as health care, self-care, and transport.

Victoria's population is forecast to grow, and its demographics change, over the coming years. This in turn will impact both the demand for, and availability of, carers. For example, a significant factor driving demand for carers will be population ageing, with forecasts suggesting there will be over 112,000 additional Victorians aged 75+ by 2026.

At the same time, societal and economic changes have the potential to reduce the number of available carers and/or the time they have available to support others at the very time when more Victorians might need that kind of care.

## The challenges experienced by carers

It is well recognised that Australians living with care needs may experience poorer outcomes in many domains of life including health, education, and employment.

Alongside this, there is extensive evidence to show similar impacts for the individual's carer(s) and family.

When unsupported and under-resourced, care responsibilities can negatively impact on the emotional and physical wellbeing of carers. Evidence shows that carers experience greater exhaustion, stress, anxiety depression, injury, and physical ill health than non-carers.

Many carers have fewer opportunities to experience social and recreational activities and have reduced capacity to participate in the Victorian economy.

<sup>1</sup> For example, in the 2020 National Carer Survey carers reported they supported the person they care for with transport (79%), administrative support 78%, household chores (77%) and cognitive or emotional tasks (77%).



There are lower rates of employment among carers, and it is not uncommon for carers to reduce their hours or take on lesser paid roles to balance their employment with their caring role. Pre-COVID-19, over 20% of carers had exited the workforce to provide care or reduced their working hours, adversely impacting both their financial situation and wellbeing. A recent survey suggests that 47% of carers adjusted their employment arrangements to accommodate their caring role during the pandemic.

A range of barriers have been identified to carers successfully balancing their caring role with employment. For example, in recent research, nearly half of the Victorian respondents indicated they could not find employment that would allow them respond to an emergency or allow them to sufficiently check-in with the person they care for.

## Impacts of the COVID-19 pandemic on carers

In late 2021, Carers Victoria surveyed carers across the state regarding the impacts of the pandemic on their caring role and what they most needed to be able to transition to COVID normal. Over 1,100 carers responded, with a high level of similarity in results across both metropolitan and regional Victoria.

Key findings included:

- › Most carers reported that the pandemic worsened their mental health and wellbeing with around 76% of respondents reporting more loneliness compared with pre-COVID-19. This is significantly higher than reported trends in the general population, where available literature suggests 54% of respondents felt lonelier since the start of the pandemic.
- › 80% of carers spent more time in their caring roles during the COVID-19 pandemic and over 50% had to provide complex care usually provided by medical and allied health professionals.
- › There were many impacts on carers' ability to combine their employment and care roles with some accepting a position that would better accommodate their care role, resigning, or early retirement.

# BUILDING A CARER FRIENDLY FUTURE – PRIORITIES FOR ACTION

## Support carer mental health and wellbeing

### RECOMMENDATION 1

Fund dedicated Carer Mental Health and Wellbeing staff in at least 20% of Local Adult and Older Adult Mental Health and Wellbeing Services so that all carers can access timely mental health and wellbeing support.

### The challenge

It has been a tough two years for many Victorians, but particularly so for many carers who, with reduced access to many supports, had the challenge of balancing their caring role alongside the many challenges the pandemic and associated lockdowns posed to people across our state.

For many carers, this exacerbated the social isolation and poorer health and wellbeing they may have already been experiencing with pre-pandemic data indicating that carers experience poorer wellbeing at 2.5 times the rate of people not in caring roles.

The individual needs of carers, particularly those related to their mental health and wellbeing, need to be considered alongside the assistance they may require to fulfil their caring role. This is a particular challenge given available evidence indicates that carers often deprioritise or neglect their own needs and health goals.

### The opportunity

For many carers, access to counselling, case management and other support services, delivered by practitioners with a deep understanding of the role and challenges faced by carers and the capacity to provide episodic, ongoing support as needed, can play a key role in helping them maintain good mental health, well-being, and resilience.

A current gap in the system is little or no access to preventive or early intervention type services that can be used to prevent a significant problem occurring.

The Royal Commission into Mental Health recognised the need for such supports for carers of people with mental health conditions.



Carers Victoria strongly supports the recommendations of the Commission and has framed this platform to support those. It does however wish to highlight that it is essential that given the poorer mental health and wellbeing status of carers, these supports be available to all carers - not only those supporting people with mental health conditions.

Carers Victoria is keen to ensure that priority is given to prevention and early intervention services for carers to minimise the mental health and wellbeing impacts of their caring role. It proposes that this be given practical effect by establishing dedicated carer health and wellbeing roles in Local Adult and Older

Adult Mental Health and Wellbeing Services (Locals), so that it is an embedded part of the future mental health architecture in Victoria.

Carers Victoria is also strongly supportive of the commitments to ensure all mental health and wellbeing services and staff understand care relationships, and both the needs and support requirements of carers themselves, as set out in the Capability Framework that forms part of the broader *Mental Health and Wellbeing Workforce Strategy 2021-2024*.

This will be an essential element to ensure carers are recognised, understood, and actively supported in Victoria's future mental health and wellbeing system.

**Carers Victoria is keen to ensure that priority is given to prevention and early intervention services for carers to minimise the mental health and wellbeing impacts of their caring role**

# Simple and flexible supports for carers

## RECOMMENDATION 2

Establish a state-wide Carer Advisory Service that can help carers navigate complex systems.

## RECOMMENDATION 3

Sustain and grow flexible funded support for carers so that 112,000 additional Victorians are receiving this support each year by 2026.

## The challenge

Often people who require care have multiple needs that span a myriad of services and systems, each of which will often have its own processes, paperwork, people, and requirements.

This means that carers currently spend a lot of time seeking to engage with, and navigate, a myriad of these systems, which rarely 'speak' to each other.

While there have been efforts to integrate some elements of support for carers, carers tell us they need a service that is simple and easy to access and can help them navigate the full breadth of systems and supports and provide practical advice and strategies to support them in doing so.

Carers also tell us that it can be difficult to access support that can help them in their caring role.

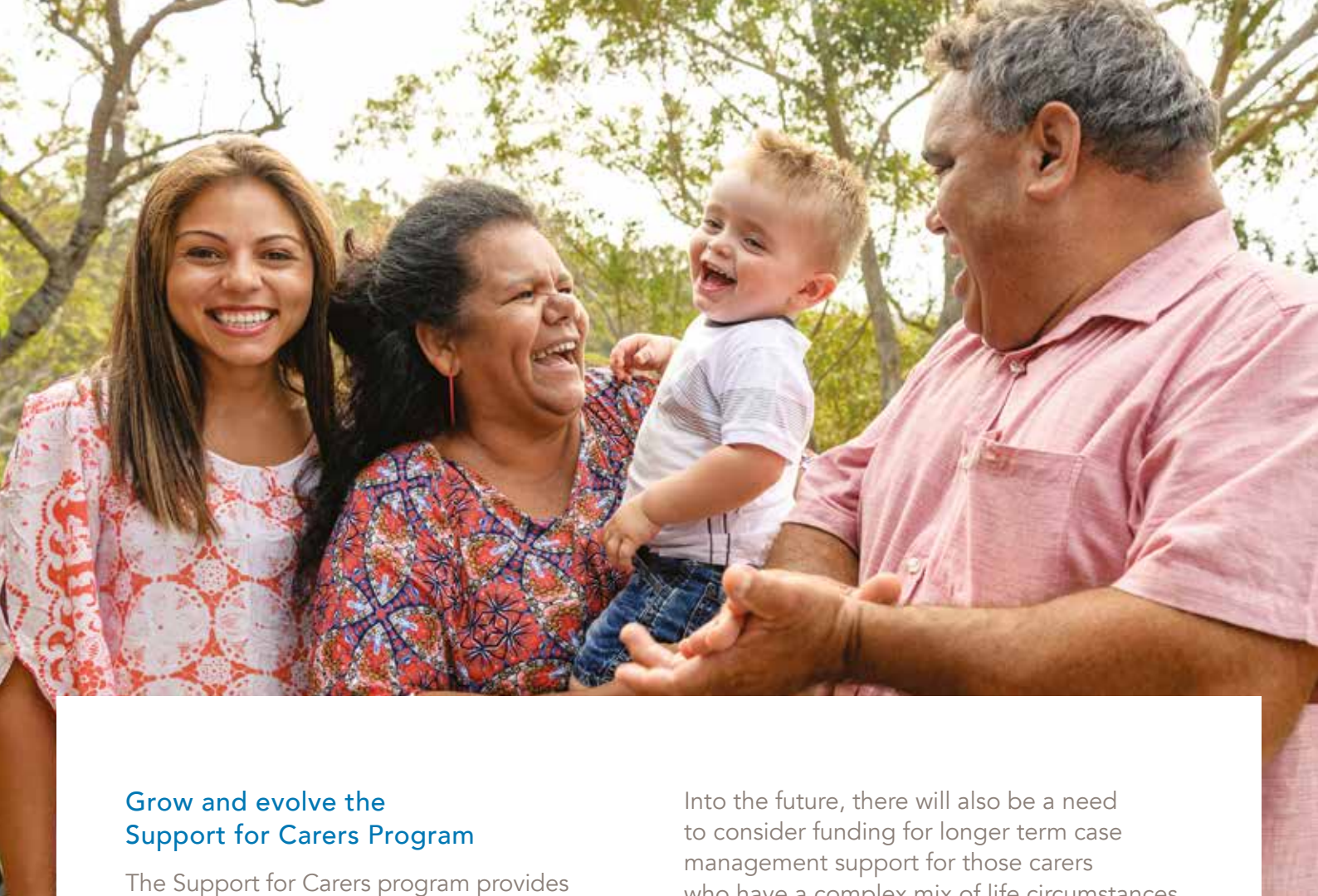
The Victorian Government's commitment to fund additional services through the Support for Carers program has been strongly welcomed but is currently a time limited commitment. With one of the largest populations relying on carers (Victorians aged 75+) due to increase by over 112,000 by 2026 there is a need to both consolidate and expand this program to meet future need.

## The opportunities

To make the system work better, targeted real-time support and advice needs to be combined with continued and growing investment in practical, carer focussed supports that can sustain carers into the future.

### A State-wide Carer Advisory Service

A funded state-wide Carer Advisory service (phone and web based) will allow carers and service providers to quickly access guidance on navigating a myriad of systems. This will save carers time and stress resulting in improved health and wellbeing for carers and people receiving care as their needs are met more efficiently.



### Grow and evolve the Support for Carers Program

The Support for Carers program provides a unique and flexible program to deliver supports that really matter to carers. Consolidating recent growth in the program and support its further expansion, at least at a level equivalent to growth in the 75+ population (many of whom will be carers or care recipients) will be important to ensure that across Victoria carers can be supported and sustained in their care relationships and can continue to make their significant contributions to both society and our economy.

Into the future, there will also be a need to consider funding for longer term case management support for those carers who have a complex mix of life circumstances which place them and their care recipient/s at high risk of reaching crisis points in their relationships, as a way of helping them navigate and proactively plan for and manage these.

Carers tell us they need a service that is simple and easy to access that can help them navigate them the full breadth of systems and supports and provide practical advice and strategies.

# Support carers in crisis

## RECOMMENDATION 4

Establish a carer focussed crisis line through which carers can seek advice and support to respond to emergencies.

## RECOMMENDATION 5

Embed specific consideration of the needs of carers into state-wide emergency planning and response activities.

## RECOMMENDATION 6

Equip carers with practical resources to plan for the future.

## The challenge

Every year, some of Victoria's carers will experience a crisis in their care relationship.

These may range from the impacts of external crises (such as fire, flood, or pandemic) through to changed circumstances within the home (such as a significant change in health status, instances of family violence or a wide range of other issues).

The common theme is that such changes mean that the care arrangements that previously were working may no longer be doing so, and immediate changes are needed to the supports, care arrangements and/or living arrangements.

These are difficult situations for any Victorian but are particularly challenging for those in care relationships, because of the vulnerability of the people involved, their additional needs, the varied nature and complexity of care relationships and the likely need to rapidly engage with multiple service systems.

Significant and unplanned changes in circumstances are particularly challenging for those in care relationships, because of the vulnerability of the people involved, their additional needs, the varied nature and complexity of care relationships and the likely need to rapidly engage with multiple service systems.

Carers also raised concerns about what might happen if, due to changes in their health or other circumstances, they are no longer able to continue in their current caring role. This is frequently referenced in relation to ageing carers of adult children (who themselves are twice as likely to experience a major change in health status than the general population) but is also a concern expressed by other carers.

## The opportunities

There are strategies that can be implemented to manage and minimise the impact of these situations on carers, care recipients and the broader health and social care systems.

### Carer Crisis Coordination Support

When there is a crisis, carers will have their hands full managing both their caring role and the impacts of the crisis on them and their loved ones.

A 24-hour, 7 day a week phone-based service that can direct them to available supports in their area and other practical advice will play a critical role in helping them minimise the impact of their situation and could also be leveraged when broader emergency management systems are activated.

### Better integrating the needs of carers into state-wide planning

In a natural emergency such as bushfire where a carer needs to leave home with the person they care for, there needs to be provision for ensuring their needs have been considered. For example, while it may be feasible for most Victorians in such situations to be self-sufficient for 48 hours, this is unlikely to be so for many carers who will need immediate help getting accommodation, equipment, supplies or other supports that meet the specific needs of the person they care for.

A specific focus on understanding the supports carers will need in these circumstances, and embedding these in state-wide planning, will enhance the emergency response and ultimately save lives.

### Equip carers with practical resources to plan for the future

Carers Victoria has received requests for plain English, simple information that might help carers know how and where to start such planning, how to have these conversations, and associated resources that are tailored to the needs of carers.

A tailored program combining resources and web-based training for carers will equip them to discuss and pre-plan for scenarios where a change in circumstances means they may no longer be able to continue their current care relationship.

# Support more carers into employment and study

## RECOMMENDATION 7

Ensure young carers are proactively supported to remain engaged in education and training.

## RECOMMENDATION 8

Consolidate and recurrently fund local pathways and architecture that supports carers into employment and training.

## RECOMMENDATION 9

Support programs that encourage employers to recruit and retain carers.

## RECOMMENDATION 10

The Victorian Public Service become a leader in carer employment, including the establishment of state-wide targets.

## The challenge

Balancing paid work and/or study with care responsibilities has always been a challenge. This has been exacerbated by COVID-19.

Pre-COVID-19, evidence suggested that around 1 in 8 employees were in a caring role. Unfortunately, many struggled to balance this with their caring responsibilities resulting in one in five carers leaving paid work.

During the pandemic, these trends were exacerbated. Recent carer survey results indicate that around half of all carers changed their employment arrangements to accommodate their caring role, with 12% resigning or taking early retirement and a further 35% making other adjustments to their employment as a result.

Similarly, caring roles can make it extremely challenging to engage in and complete education and training, with available data suggesting that young carers are significantly more likely to disengage from and/or drop out of school than their peers.

These impacts on participation in both training and employment has major impacts for the lives of carers, their future employment opportunities, and their overall financial status.



## The opportunities

There is an untapped opportunity to support Victorian carers who wish to access or maintain employment or study by tackling some of the key barriers experienced.

At a time when employers are experiencing substantial workforce shortages across many industries, an active strategy that assists carers to enter or remain in employment offers significant social and economic benefits not just to carers but also to employers, and others in the Victorian community.

The Victorian Government has prioritised carers in both schools and the employment and training areas. There is scope to enhance this work given data indicates continuing challenges.

Carers Victoria is seeking:

- › **Strengthened support for young carers** through additional strategies that can help them balance their study and caring roles. To benefit all young carers this needs to build upon the fantastic commitments to young mental health carers.
- › **Recurrent funding to roll out and consolidate local carer pathways to employment and training state-wide**, building on the findings of the pilot projects run by Neighbourhood Houses Victoria and Carers Victoria.
- › Work with Carers Victoria to increase employment of carers and provide practical support and advice to support retention, drawing on the carer friendly workplaces concept.
- › A commitment to the *Victorian Public Service becoming a leader in carer friendly workplaces* and setting minimum targets for recruitment of carers.

At a time when employers are experiencing substantial workforce shortages across many industries, an active strategy that assists carers to enter or remain in employment offers significant social and economic benefits not just to carers, but also to employers, and others in the Victorian community.

# Integrate carer expertise and input into key service systems

## RECOMMENDATION 11

Recognise the role and expertise of carers in legislation governing health care, disability, mental health, and other relevant areas.

## RECOMMENDATION 12

Ensure carers are actively involved in advisory structures shaping government program design, implementation, and review.

## RECOMMENDATION 13

Establish a program to support carers in taking up an active role across key service systems.

## The challenge

Carers are everywhere. The things they do every day are not only essential to the effective operation of our health and social care systems, but many of them combine that with paid employment, volunteering, and other contributions to our community.

This delivers both social and economic benefits, yet carers regularly tell us that they are excluded from key meetings that impact their ability to provide unpaid care, or struggle to get the basic information they need, or that their perspectives and advice is ignored.

The Royal Commission into Mental Health recommended that a combination of awareness raising, information sharing, and training was needed to ensure the expertise and input of carers was integrated into the mental health system.

Carers are everywhere. The things they do every day are not only essential to the effective operation of our health and social care systems, but many of them combine that with paid employment, volunteering, and other contributions to our community.



Carers Victoria strongly supports this investment in capacity building. The same challenges exist for carers of people with other conditions and Carers Victoria is calling for a program that will provide the training, information sharing protocols and awareness raising across Victorian health, disability, and aged care settings.

While the Victorian Carer Recognition Act established a basic legislative instrument to recognise carers and their valued role in society there is still a long way to go. For example, data suggests that only 20% of carers feel that governments value their caring role.

This needs to change and there are some very practical actions that can support that change so that in the future, the role of carers and their expertise is recognised and brought to bear in the design, planning and review of systems and supports that impact the people they care for. This needs to include the specific experiences and insights of young carers.

## The opportunities

Carers Victoria is calling for:

- › **the role of carers and their expertise to be recognised in key legislation and planning processes** across areas such as disability, health care, and other areas of social care, requiring them to be included in advisory, governance, and planning processes;
- › **support for a program to expand the skills and expertise of people with lived and living experience of caring** so they can maximise their contribution to these processes.

These actions by government would support other proposed strategies to increase the awareness, understanding and support for carers across corporate and other sectors.

# SUMMARY OF RECOMMENDATIONS

## RECOMMENDATION 1



Fund dedicated Carer Mental Health and Wellbeing staff in at least 20% of Local Adult and Older Adult Mental Health and Wellbeing Services so that all carers can access timely mental health and wellbeing support.

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## RECOMMENDATION 2



Establish a state-wide Carer Advisory Service that can help carers navigate complex systems.

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## RECOMMENDATION 3



Sustain and grow flexible funded support for carers so that 112,000 additional Victorians are receiving this support each year by 2026.

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## RECOMMENDATION 4



Establish a carer focussed crisis line through which carers can seek advice and support to respond to emergencies.

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## RECOMMENDATION 5



Embed specific consideration of the needs of carers into state-wide emergency planning and response activities.

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## RECOMMENDATION 6



Equip carers with practical resources to plan for the future.

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### RECOMMENDATION 7



Ensure young carers are proactively supported to remain engaged in education and training.

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### RECOMMENDATION 8



Consolidate and recurrently fund local pathways and architecture that supports carers into employment and training.

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### RECOMMENDATION 9



Support programs that encourage employers to recruit and retain carers.

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### RECOMMENDATION 10



The Victorian Public Service become a leader in carer employment, including the establishment of state-wide targets.

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Recognise the role and expertise of carers in legislation governing health care, disability, mental health, and other relevant areas.

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### RECOMMENDATION 13



Establish a program to support carers in taking up an active role across key service systems.

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