



Recognising and supporting Victoria's carers

Victorian carer
strategy 2018–22

Acknowledgement of Aboriginal Victoria

The Victorian Government proudly acknowledges Victoria's Aboriginal communities and their rich culture and pays respect to their Elders past and present. We acknowledge Aboriginal people as Australia's first peoples and as the Traditional Owners and custodians of the land and water on which we live, work and play. We recognise and value the ongoing contribution of Aboriginal people and communities to Victorian life and how this enriches our society more broadly. We embrace the spirit of self-determination and reconciliation, working towards equality of outcomes and ensuring an equitable voice.

Victorian Aboriginal communities and peoples are culturally diverse, with rich and varied heritages and histories both pre and post-invasion. The impacts of colonisation – while having devastating effects on the traditional life of Aboriginal Nations – have not diminished Aboriginal people's connection to country, culture or community. Aboriginal Nations continue to strengthen and grow with the resurgence of language, lore and cultural knowledge. These rich and varied histories need to be understood and acknowledged by all Victorians, to truly understand the resilience and strength of previous generations, as well as the history of the fight for survival, justice and country that has taken place across Victoria and around Australia.

As we work together to ensure Victorian Aboriginal communities continue to thrive, the government acknowledges the invaluable contributions of generations of Aboriginal warriors that have come before us, who have fought tirelessly for the rights of their people and communities towards Aboriginal self-determination. We are now honoured to be part of that vision.

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Where the term 'Aboriginal' is used it refers to both Aboriginal and Torres Strait Islander people.

Indigenous is retained when it is part of the title of a report, program or quotation.

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Minister's foreword



Across Victoria, more than 736,600 carers give their time, effort and love to caring for a family member or friend who needs them.

Carers come from all walks and stages of life. They may care for a parent or grandparent, a child, a partner, a sister or brother, or a close friend, who has specific care needs. Some carers care for more than one person at a time. Carers are a mix of ages from people in their eighties and nineties to young children – in fact, thousands of children care for a parent, or help care for a sick sister or brother. We know that the care role has a huge impact on the lives and opportunities of all carers, especially young carers.

Whenever we speak with carers, they tell us that caring is extremely rewarding. But it's also hard. It can be difficult to find the information and services they need, and to balance their needs and the needs of the person they care for. And the reality is, any one of us might find ourselves in a care relationship one day.

Recognising and supporting Victoria's carers: Victorian carer strategy 2018–22 is the first whole-of-government strategy to support carers in their own right. The strategy sets the direction for government to support carers. By releasing this strategy, we acknowledge the vital work that carers do, and the role they play in the Victorian community. We have written this strategy based on what carers have told us in consultations around the state. We have also drawn on broader government policies such as the *State disability plan 2017–20*, *Victoria's 10-year mental health plan* and *Korin Korin Balit-Djak: Aboriginal health, wellbeing and safety strategic plan 2017–27*. We aim to make sure that, over time, all Victorian carers have the support and services they need and want, no matter where they live, or their age.

This strategy provides a framework for the many undertakings and investments the Victorian Government has already made to support carers, as well as future work to address the things that matter most to carers.

Government cannot do this alone. To better support carers, we need to work with our partners in the community, human services and health sectors, including primary and allied health professionals, public and private health services, not-for-profit organisations, local government, businesses, workplaces, schools and carers themselves.

The Victorian Government will continue to champion carers' needs with the Commonwealth and seek expanded access to the support and services Victorian carers need and deserve.

We want to thank all the carers in Victoria for the support you offer to the people you care for. For too long, your work has been unrecognised. We hope this strategy, and the actions it contains, are a positive step towards giving you access to the information, services and support you need to continue your crucial role in our community.

A handwritten signature in black ink, appearing to read 'Martin Foley'.

Martin Foley MP
Minister for Housing, Disability and Ageing

Parliamentary Secretary's foreword



Carers make a significant and unique contribution to Victoria.

As Parliamentary Secretary for Carers and Volunteers, I have been fortunate to meet with many carers from different backgrounds and different parts of our state.

I have also met with many organisations supporting our carers – including organisations that support specific kinds of carers, like young carers and carers of people with a mental illness.

This has been a profound opportunity to hear first-hand about what matters most to our state's carers, and I'd like to thank every carer and every family that has taken the time to share their story.

In developing the Victorian carer strategy 2018–22, the Victorian Government has made sure the voices and experiences of carers are central. This includes working closely with Carers Victoria, providing funding to consult directly with carers, and the organisations and service providers that support them.

Through this consultation, we have heard about the different and distinct challenges faced while caring for someone, and about how we can better support carers in meeting those challenges.

Through this strategy we hope to address stereotypes about carers, to better acknowledge hidden carers and ultimately improve the support for carers in our community.

Carers have so much to contribute.

They have well-developed skills in caring, in-depth knowledge of the person they care for, as well as sharing a deep personal bond.

We want to better acknowledge and appreciate the unique and valuable insights carers have into the needs of the person they care for.

This strategy also focuses on health and wellbeing, acknowledging that carers often don't have the time, energy or opportunity to take care of themselves. We want their physical and mental health – and their connections to family, friends, local communities – to be better supported, as well as connections to other carers for peer support.

We want young carers to be able to continue in education, and other carers to be able to access education. And, for those who choose to, we want carers to be able to enter, re-enter or stay in employment.

The strategy includes supports for carers from all walks of life – whether studying, working or contributing to their community in other ways. Importantly, this strategy will help meet the many different needs of this very diverse group of people, and provide easy to access information about the services and supports available.

Any of us can become a carer at any time. And having grown up in a family of carers, the development of this strategy is very important to me.

It is my sincere hope that every carer – and everyone who has had a supportive care role for another person – finds this strategy reflective of their experiences, and of benefit to their future.

Gabrielle Williams

Gabrielle Williams
Parliamentary Secretary for Carers and Volunteers

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Introduction

The Victorian Government knows how important carers are – not only to the people they care for, the people whose lives they improve on a daily basis, but to the whole community.

Carers provide support to partners, family and friends. They care for someone with a disability, mental illness, terminal illness, chronic illness, or an older person with care needs.

Victoria's carers are as diverse as the people they care for. They provide emotional and practical support, and provide this care anywhere from a couple of hours a day to around-the-clock assistance.

The care role can be hugely rewarding for the carer, but it can also be challenging. It can be difficult to make sure carers get access to the services and supports they need to look after themselves and make sure they're supported in their care role – particularly since many don't identify as carers.

In preparing this strategy, we spoke with about 1,500 carers as well as carer support organisations to better understand the challenges, needs and wants of Victoria's carers. Their input informs every aspect of this whole-of-Victorian-Government strategy.

Quotes from these consultations are scattered throughout this strategy to give voice to the many carers who gave their time to share their insights with us. To those carers, and all the other carers across Victoria who give their time each day to care for someone else, we are most grateful.



The valuable role of Victoria's carers

Carers make a valuable contribution to our community on many levels. They give their time, effort and love to caring for a family member, partner or friend who needs them.

Carers provide much needed support to those who need it

Often, there is no-one else who can deliver the support that our carers provide. We recognise the role and strength of carers. Carers provide every different type of support there is.

Carers help with physical tasks such as eating, cooking, toileting, showering, dressing, administering medication, managing appointments with health professionals, property maintenance and helping with transport.

They also provide emotional and social support, and often provide communication support.

Carers contribute to the economy and our community

All carers are experts in caring for the person they support; they understand the person's needs and preferences better

than anyone. We also know that carers make a positive contribution to our economy. The annual cost of replacing the support provided by Victorian carers is about \$15 billion.

Carers are valued members of the entire community, not just to those they care for. Through the requirements of their day to day roles, carers often possess valuable skills in problem solving, multi-tasking and managing complex social and medical systems.

Being a carer

Being a carer affects people in different ways and at different stages of life. We know that caring can be incredibly rewarding. Some carers identify many positive aspects of their care role, including skills development and a sense of personal fulfilment.

However, being a carer can also mean missing out on ordinary things you would usually do and have. Carers may lose contact with other people, become lonely, lose their job or have shifts cut, drop out of study, or not have time to look after or enjoy themselves. Carers may have limited financial stability making it hard to pay bills, buy the equipment or make the modifications to their home they need to support someone.

Research shows that caring, especially if it's for more than 40 hours a week, means carers are less likely to participate in activities outside the home such as cultural, recreational or physical activities, especially without the person they care for.

Carers who provide more than 50 hours of care a week are twice as likely as non-carers to become ill. Some carers put off going to a doctor because they need to support their partner, relative or friend. Many, if not most, carers will spend lots of their time in healthcare settings, but will rarely have their own health needs identified or addressed.

'Don't see being a carer as a burden. Caring can enrich your life.'

Consultation participant

'My partner was supposed to be receiving 24-hour care, and he couldn't be left alone. Although I had chest pains, I discharged myself from intensive care to go home and look after him because the carers were knocking off.'

Carer of an older person

The reality of many carers is that they always put the person they support first. Their own needs can become secondary. This can take a physical toll, and it can make carers feel alone, tired, burnt out, guilty or resentful, and these feelings can affect their health and wellbeing. Carers often find themselves needing to tell and retell their story to services, which can be frustrating, exhausting and inefficient. This can also have a negative impact on a carer's health and wellbeing, and carers may need different types of support at different times.

Being a carer can also affect personal relationships. When one person needs to be cared for in a significant way by the other, it is an important shift. As the needs of one partner increase, the responsibilities of the other person usually grow. Where people may have supported each other on an equal basis, one person gradually becomes the carer. The relationship dynamic can change, sometimes leading to a relationship breakdown.

Caring for a child with special needs can also place strain on a couple's relationship. Couples may deal with the stress of caring differently and become disconnected from each other. A care role may become time consuming, meaning less time and energy are dedicated to other important relationships.

For female carers of a person with a disability, about one in three female carers aged 50 or younger separate or divorce from the time they start caring; one in seven over the age of 50 separate or divorce from the time they start being the carer.

In some cases, people become a carer for an ex-partner years after the personal relationship has ended.

For female carers of a person with a disability:



1 in 3

aged 50 or less, separate or divorce from the time they start caring.

1 in 7

over the age of 50 separate or divorce from the time they start being the carer.

Who are Victoria's carers?

Carers are ordinary people who make a huge contribution to our community and to the people they care for. There are more than 736,600 carers in Victoria and, of these, 239,100 are primary carers. A primary carer is someone who provides most of the care for another person. More than a third of primary carers have a disability themselves.

70%

of primary carers are female



75%

of carers are between 15 and 64 years of age

25%

of Victorians over 55 years of age are carers

52%

of carers work



25%

of working carers spend 40+ hours a week providing care

3-4%

of employees become carers each year

10%

of Victorian carers are under 25



there are over

71,600

young carers

young carers are **often hidden** in the community



Most primary carers become carers for several reasons. The most common reasons include a sense of family responsibility (67 per cent of carers), a feeling that carers can provide better care than anyone else (about 50 per cent of carers) and a sense of duty (44 per cent of carers).

Carers are diverse

Every carer is individual in their needs and experiences. The needs of carers and the people they support can change as their lives change.

Some carers do not want to be 'labelled' as carers, but they want to be acknowledged for their care role, and want to be respected and supported. We want all carers to have appropriate support and services that benefit them and their care relationship.

Hidden carers

Many carers do not identify as such. Often they take on a care role because they see caring as a family duty. There are also some forms of caring that are less visible to the community, including caring for someone with an episodic mental illness. Some carers may not identify as a carer as they feel the need to protect the person they care for from stigma and discrimination related to their illness or disability. By not being seen or recognising themselves as a carer, many carers may not access the services and support they need. They are also less likely to have their care role recognised, which may lead to challenges in workplaces, education, and social relationships.

Young carers

Young carers (under the age of 25) often care for a parent or grandparent, or a sibling with a chronic illness, mental illness, disability or drug/alcohol addiction.

Many children and young people with care responsibilities don't identify as carers. Often, others don't see them that way either. Lack of support during a person's formative years can have lifelong effects on cognitive and social development, learning and education, work opportunities, finances, emotional and mental health and physical health.

Research shows that young carers are less likely to go out or to entertain friends at home. This can lead to social isolation, loneliness and loss of friendships. They are also less likely to have support networks around them to help or listen and are less likely to seek help. Young carers are often financially disadvantaged and have fewer job opportunities. They may not recognise or be able to articulate the additional challenges their care role may present, which means they may be less likely to ask for help.

Young carers care for a parent or grandparent or sibling with a chronic illness, mental illness, disability or drug/alcohol addiction



1 in 10

Victorian carers are under the age of 25.

Almost 2 per cent of children under the age of 15 years and 7.4 per cent of 15-24 year olds say they help someone with care needs who is older, who has a long-term sickness or a disability.

On average adolescents who support someone at home for at least 2 hours per day fall up to 18 months behind in reading at Year 9 level, and 15 months in maths.

On average young carers miss about 50 school days each year because of their care role.

More than 50 per cent of university students who are carers struggle with their studies because of their care role.

'At my last school, there were four or five teachers who just said no if you asked for an extension. Even if you were going through the hardest moment in that year, they still said no, wouldn't understand, just dismissed it.'

Consultation participant

Older carers

The average age of primary carers is 55 years. More than 162,000 carers are aged 65 years or older.

Many care for their partners, older parents, adult children and/or grandchildren.

162,000+

**carers are
aged 65 years
and over**



55 years

**Is the average age of
primary carers. Many
care for their partners,
older parents, and
adult children.**

Older carers mainly take on the care role of people 65 years or older because no other friends or family are available. Older carers face a major challenge in caring for their own health and wellbeing as they get older while providing care for others, and may need supports in place when future planning is required for the person they care for.

LGBTI carers

Lesbian, gay, bisexual, trans and gender diverse and/or intersex (LGBTI) carers can experience discrimination based on their gender and/or sexuality. They may have poor health and wellbeing because of lack of access to inclusive services. Even though many health professionals understand the importance of recognising and engaging with LGBTI carers, some people may still experience discrimination and exclusion in health care settings.

While many spouse or partner carers are recognised by service providers for their carer role, their relationships may not be recognised. This can lead to

carers from LGBTI communities feeling unacknowledged, unsupported, isolated, marginalised and stigmatised.

Aboriginal carers

Aboriginal Victorians are more likely than non-Aboriginal Victorians to identify as carers and to support a friend or family member. Culturally appropriate services that acknowledge and respect Aboriginal kinship structures and potential privacy concerns are often not available to Aboriginal people and their carers.

About 30 per cent of Aboriginal people with a disability live in outer regional and rural areas, making it hard for them and their carers to access services and to pay associated costs. These issues imply a higher reliance on unpaid care in Aboriginal communities.

'I am now in my sixties and still caring for my daughter with high healthcare needs. I would like to take some time off and see my sister overseas. This is an almost impossible dream! It may become real if people see support or respite as helping a carer, as well as the person with a mental illness.'

Carer of an adult daughter with care needs



Culturally diverse carers

Nearly 50 per cent of Victorians are born overseas or have at least one parent born overseas. Culturally diverse carers often need information in languages other than English about services and access to culturally appropriate supports. Services do not always have bilingual staff or an in depth understanding of different cultural, religious and spiritual beliefs, and family relationships. These factors can create additional barriers for culturally diverse carers and lead to poor health and wellbeing.

In culturally diverse communities experiences prior to arriving in Australia may have been traumatic and can affect people in care relationships. Carers can feel alienated from extended family and social support – for example, stigma or a lack of understanding within their communities about disability

and mental illness. There can be intergenerational differences in cultural beliefs and values about caring for older people. Younger generations may face increased financial pressures and have to make work or lifestyle choices that mean their ability to take on a carer role is limited.

Employed carers

Balancing work and care responsibilities can be challenging. About one in five carers give up work to care for someone. Only 56 per cent of primary carers are in the workforce compared with 80 per cent of non-carers. The weekly median income of a primary carer is \$520, which is 42 per cent lower than a non-carer.

Combining paid work and caring means carers are often working part-time or casually, or in a job below their skill level. Demands on their time outside of work can mean carers are seen as unreliable in the workplace. Difficulty in keeping a job can leave carers financially disadvantaged.

However, carers often have unique skills to contribute to workplaces – they can navigate complex systems and are good at solving problems. Unfortunately, these skills often go unrecognised in workplaces or by potential employers.

Regional and rural carers

Carers living outside major cities are more likely to report strong social networks and to know someone they can ask for information and advice. This is important because carers in regional and rural Victoria are less likely to have health and support services nearby and may need to rely more on

mobile or visiting services, along with online and phone services.

However, carers in outer regional areas experience higher rates of disability or long-term health problems. They have lower employment rates than carers in metropolitan areas. They are more likely to live in a jobless household and experience greater financial hardship. Services need to be responsive to these additional needs of carers in rural and regional Victoria.

Parents of those with care needs

While caring for a child under 18 years of age with a disability, mental illness or complex care needs, parental care roles and responsibilities are commonly recognised and respected. However, parents often experience a lack of recognition of their ongoing

role in supporting an adult child with care needs. Parent carers can find it hard to meet personal goals and aspirations. As they get older, many parent carers find it more difficult to care for their adult child and may require specific supports to assist in future care planning for their child.

Carers with an illness or disability

Nearly 38 per cent of primary carers have a disability compared with 16 per cent of non-carers. Male primary carers are more likely to report living with a disability than female primary carers. However, similar proportions of male and female primary carers report having a profound or severe limitation. The majority of carers with a disability have a physical condition, such as back problems, as their main longterm health condition. Many of these carers also struggle with mental health challenges. Carers with an illness or disability can find it hard to meet their own health and wellbeing needs and may put themselves second while caring for someone else.

Kinship, foster and permanent carers

Kinship, foster or permanent carers care for children who, for a range of reasons, may not be able to stay with their parents. Some children placed with kinship, foster or permanent carers may have additional care needs. In these cases carers are entitled to the range of benefits and supports in place for all Victorian carers.



Who do Victoria's carers care for?

The people carers support are also diverse and their needs can vary. Carers support people with a mental illness, disability, chronic illness or complex care needs. They care for older people with specific needs, children and young people with additional care needs, and people who are dying.



Older people

More than one in three people aged 65 years or older need assistance with daily activities. People who are the primary carers for their parent(s) are most likely to be 45–64 years of age, and most of them are women. While most carers aged 65 years or older care for their spouse or partner, nearly nine per cent of primary carers aged 65 or older care for their parent. People caring for their parents or parents-in-law and people caring for their spouse or partner often need distinct supports for different stages of their carer journey.

Navigating the aged care system can be stressful and confusing and carers of older people may need additional assistance. Many carers could also benefit from formal and informal support with particular aspects of their role such as becoming a carer, adjusting to changes in the health of the person they care for (and changes to their own health), moving to residential aged care and specific support if the person they care for passes away.

'Being a carer, sometimes you walk behind the person you're caring for, sometimes beside them, and sometimes in front of them.'

Consultation participant

People with complex health needs

Carers support people with complex health needs including diverse types of illness and conditions. Caring for someone with multiple complex health needs can be very challenging. A person's health may deteriorate over time. Their multiple conditions might have complex symptoms. They may also struggle with mental illness. For different illnesses, the changing needs of a person are matched by periods of changing intensity of caring and the need for constant adjustment.

To best support a person to provide care in the way they prefer, service providers need to better recognise and support carers when they access the health system. This includes recognising carer needs in supporting a person's care preferences.

People with a disability

Many carers support a person or people with a disability including children and adult children.

No two people living with a disability have the same needs, or care requirements.

Many carers of people with a disability believe the person they care for will be supported by the National Disability Insurance Scheme (NDIS). At the same time, we acknowledge some carers have genuine questions or concerns about their role under the NDIS. The Victorian Government will keep working with carers and families to address these issues.

People with a mental illness

Carers of people with a mental illness often face unique challenges. Mental illness can be unpredictable, episodic and less visible to the community, and the role of a carer can go unrecognised or be misunderstood. Mental illness can be stigmatised, particularly in some culturally diverse communities, stopping people from accessing the support they need.

Mental illness is different for everyone. Some people with a mental illness can be well most of the time but have times when they need a lot of support. Carers of people with a mental illness can feel shut out of meaningful discussion with psychiatrists or other mental health professionals because of client privacy. This can make caring more difficult.

People with dementia

Caring for someone with dementia can be confusing, worrying and uncertain. Each person with dementia experiences their illness and its symptoms differently. People in the early stages of dementia and their carers may need help to make plans for the future, such as with drafting powers of attorney and advance care plans.

Carers need different supports as the disease progresses – from the early symptom stage, to referral to assessment services, after a diagnosis is made, through to end-of life care.

What is the Victorian Government's commitment to carers?

The Victorian Government is committed to continuing a wide range of existing supports, programs and services for Victorian carers. Through this strategy the Victorian Government will be doing more to support our carers, particularly carers who have been unrecognised or under-recognised. Victorian carers also benefit from a range of Commonwealth Government programs, payments and services to support carers.

What support do we currently provide?

The Victorian Government already supports carers via:

- the *Victorian Carers Recognition Act 2012*
- information, counselling, education, training and networking support for carers
- the Support for Carers Program, which provides respite and support for older carers, carers of older people and carers of younger people with dementia
- the Victorian Carer Card, with benefits that recognise the role of carers including transport concessions
- the Companion Card for a person with a significant and permanent disability, which allows a carer to go with the person to some public events for free
- the Victorian Mental Health Carer Support Program including carer consultants, carer resource workers, the Carer Support Fund and other resources
- various discounts and concessions including for energy, rates, water, hardship, health, communication, finance, transport and recreation
- palliative care services that support carers of people with a life-limiting illness
- programs offering information, advice and allowances to kinship, foster and permanent carers
- the Victorian Aids and Equipment Program
- the Victorian Disability Advocacy Program, which supports people with a disability and their carers
- funding organisations to support people with a disability, families and carers to move to the NDIS through the Transition Support Package
- supporting organisations to move to the Information, Linkages and Capacity Building (ILC) part of the NDIS to improve outcomes for people with a disability, families and carers
- rolling out the Changing Places initiative, which builds accessible toilets that have extra features and space to better meet the needs of people with a disability and their carers
- supporting health services to identify and consider the role and needs of carers and refer them to support services



- establishing and fostering collaborative partnerships with consumers and carers through public health networks
- the Government is undertaking significant reforms through the Roadmap for Reform: strong families, safe children to better support carers within the child and family system, including implementing a new model of kinship care, investing in therapeutic models to strengthen home-based care, and
- providing support and training for carers such as Carer KaFE and the Permanent Carer Hotline.
- initiatives in education to support students with a disability and their carers to continue participating in school
- continuing to work with Aboriginal community-controlled organisations that support Aboriginal carers, families and community members
- supporting various organisations that support carers such as Carers Victoria, Tandem and Little Dreamers
- continuing to work with the Commonwealth Government to improve understanding about what Victorian carers really want.

‘These services are great and invaluable. I don’t think we could have managed caring if the carer support services were not available.’

Consultation participant

How did carers contribute to the strategy?

In developing *Recognising and supporting Victoria's carers: Victorian carer strategy 2018–22*, we took the time to listen to what carers said and what they need and want. Carers Victoria consulted with carers and support organisations across the state.



Carers told us what sometimes happens

Carers can experience discrimination in accessing education, employment, housing and health care because of their care role.

The stigma often experienced by people with cognitive impairment and/or mental illness can also be felt by their carers. Actions of carers can be seen as causing or contributing to a person's illness.

Carers can also be seen as a 'welfare recipient' when they receive a Carer Payment or Carer Allowance, including that they are being 'paid' by the government to provide care.

When carers experience stigma and discrimination it can contribute to their own social isolation and poor physical and mental health.

Family violence can occur in care relationships, and can be perpetrated by the person being cared for or the carer.

Carers told us what works for them now

Carers get support from building relationships with staff, organisations and from each other through carer groups. Carers value counselling, support workers, peer support, short-term accommodation, funded respite services and information about what is available.

Young carers like mentoring programs, study support, social interaction, and programs such as healthy lunches provided by schools, which save time and make life easier.

Carers also value financial and transport support to help them manage day to day.

Carers told us what is not working well

Carers all have different needs at different times, and those needs are not always recognised. Services do not always support carers as individuals with their own needs. Services are not always local and do not always suit all ages, gender, sexual and cultural diversity.

Carers report that services for individuals can result in loss of funding for carer support groups, carer-directed support and carer-specific services. These supports and services help carers to continue their care role and to look after their own health and wellbeing. As the NDIS rollout continues, it's imperative that carers are included in its implementation and feel respected and recognised.

Many carers find it tough financially and feel financially disadvantaged – for example, having to work part time or make career sacrifices because of care duties.

Carers can feel disrespected or invisible in health settings. They may feel that their insight and skills are not recognised, or are ignored.

Carers can feel overwhelmed and ill-equipped, especially when they are called in to a care role suddenly. They are not always sure where to go for information and support, and may need guidance in how to meet the physical and emotional needs of the person they are caring for, as well as their own.

Carers told us what they want

Through the consultations, carers across Victoria had lively and interesting discussions about their needs. Their suggestions about how to improve support for Victorian carers included a huge range of ideas that have been considered in developing the actions in the strategy:

- support to achieve better health and wellbeing among carers
- support for carers in school, study and work environments
- access to support and services that meet carer needs
- reduced financial stress for carers
- better recognition, acknowledgement and respect for carers, especially in health, education and employment settings.



'Work provides not only much-needed income, but also validation that I am an ok person. My care recipient often expresses anger and harsh criticism towards me, and my paid work provides balance as I am treated with respect and provided with positive feedback. A good workplace can keep you sane.'

Consultation participant

Recognising and supporting Victoria's carers

A whole-of-government Victorian carer strategy

Our vision is that all Victorian carers have the ability to make choices about their care role, to participate socially and economically and to have the best health and wellbeing possible.

Priority 1

Carers have better health and wellbeing

Priority 2

Carers are supported in school, study and work environments

Priority 3

Carers can access support and services that meet their needs

Priority 4

Carers have less financial stress

Priority 5

Carers are recognised, acknowledged and respected

Our focus for 2018 to 2022 is:

- More opportunities for carers to be physically and mentally healthy and socially connected to family, friends and their local community
- Accessible carer peer support and grassroots community support programs and services

- More opportunities for young carers to complete their education and participate in peer group activities
- Workplaces that recognise and support employees to balance work and care responsibilities
- Access to support and training for carers of all ages to remain in or re-enter the paid workforce and meet other responsibilities

- Services that better support individual carers' needs and care roles for all population groups
- Accessible information about support and services for carers and an easy-to-use service system

- Programs that support financial stability and housing for carers
- Access to transport options for carers

- Better acknowledgement and recognition of carers across Victorian communities
- More identification of hidden carers, with support and services provided to meet their needs
- Involvement of carers in decision making about services and programs for the people they care for

Principles that support the strategy

Care relationship principles in the *Victorian Carers Recognition Act 2012* and the *Victorian charter supporting people in care relationships* guide program development and service delivery.

Carers are recognised and respected as individuals, with equal rights to achieve their unique health, social, education, employment and financial goals as other Victorians.

Carers are involved and their needs, preferences and voices are reflected in the design and delivery of services.

Services measure and report on how well carer needs are met using feedback from carers to improve support.

Carers are recognised as being from diverse backgrounds, ages, stages and places, and for providing support to a variety of people with a variety of unique needs.

Information for carers is easy to understand and available in places where carers go.

Carers have better health and wellbeing

Priority 1

Carers told us they want their health, wellbeing and social needs met. They want peer and family support along with peer and professionally led social activities. They see real value in support groups to help them in their day-to-day lives. They also want barriers to participating in recreational, sporting and social activities reduced.

Carers told us about the impact of caring on their mental wellbeing, both in a daily, ongoing sense and at high-stress times such as changes in their own needs and the needs of those they care for.

What will be different

- Victorian carers will have more opportunities to be physically and mentally healthy and to be socially connected to family, friends and their local community.
- Victorian carers will have better access to carer peer, professionally-led and community-led support and grassroots community support programs.

Priority actions

- Promote carer-specific and general health and wellbeing programs on the 'Everything Carers' website.
- Increase the opportunities for carers to participate in physical and social activities and programs through revising the Support for Carers Program guidelines and including carers in the Victorian Active Ageing Partnership.
- Develop resources and tools for local organisations to increase participation opportunities for older people and their carers in their local communities.
- Enable support programs for carers to connect with each other to help them access services close to where they live.
- Continue to support carer groups to hold statewide and local events and to access supports such as Carers Week activities, partnering with local councils, carer support and community organisations, neighbourhood houses and men's sheds.
- Work with Primary Health Networks to establish mental health and wellbeing support network options for all carers including access to e-health services.
- Improve opportunities for carers to get supports for their own wellbeing when the person they care for resists opportunities for respite.

'One of the biggest problems I had when I started caring for my daughter was I really felt my wings had been clipped, and I couldn't do anything else. I found a lot of my friendships fell. I found it really hard being so house-bound. I did actually have to go to counselling and I was diagnosed with depression because I was so restricted.'

Consultation participant

Carers are supported in school, study and work environments

Priority 2

Carers told us they want flexibility in the education system and at work. Young carers told us they want schools to have an understanding about their needs as young carers and how their care role affects their ability to fully participate in education, training and extracurricular activities. Working carers told us they want workplaces to have an understanding of carer employees, and to provide practical support.

What will be different

- Young carers will be supported to complete their education and participate in peer group activities.
- Workplaces will recognise and support employees to balance work and care responsibilities.
- Victorian carers will have better access to support and training to remain in or re-enter the paid workforce and meet other responsibilities.

Priority actions

- Enhance programs that help young carers to stay connected to friends and remove barriers to participating in recreational, sporting and social events.
- Work with education providers to better recognise young carers. Use proactive and flexible support arrangements so that young carers can continue to participate in primary, secondary and tertiary education and training.
- Work with education organisations to identify how they can better support parent carers through linking school communities with the Better Health Channel and the 'Everything Carers' website.
- Work with employers to develop and implement carer-friendly workplace guidelines that enable carers to continue to participate in work and promote wellbeing.
- Continue to implement and promote *Keeping our sector strong: Victoria's workforce plan for the NDIS*, which promotes working in the disability sector, to provide new employment opportunities for people in care relationships.
- Work with WorkSafe to develop resources for employers to support the mental health and wellbeing needs of carers as part of the WorkSafe WorkWell program.
- Provide information to employers on how they can better support carers who work and carers returning to work through health.vic.gov, WorkSafe WorkWell, [beyondblue](http://beyondblue.org.au), the Seniors Card business newsletter, Carers Victoria and other carer support organisations.
- Work alongside the National Disability Insurance Agency for greater potential access to education and work environments for people with a disability, their families and carers.
- Increase carer understanding of the support people in care relationships can receive through the NDIS for potential education and employment opportunities, including through the Information, Linkages and Capacity Building (ILC) part of the scheme.

'I've worked out a special plan with my school where I'm doing four subjects over three years, instead of five subjects over two years. Doing six subjects, that's normal for my school – I just wasn't able to function and I was drowning in work. I had to go to my year-level coordinator because I knew I wasn't coping. It's definitely reduced the stress load, but it's still kind of stressful.'

Consultation participant

Carers can access support and services that meet their needs

Priority 3

Carers told us they want more services to suit their needs and they want the service system to be easier to navigate. They want easy-to-find, plain-language, pictorial or translated information about services. They want a system that means they don't have to repeatedly tell their stories to health professionals and organisations.

What will be different

- Victorian carers will have access to better services and programs that support individual needs and care roles for all population groups.
- Victorian carers will have accessible information about services and an easy-to-use service system.

Priority actions

- Investigate options for reviewing the Support for Carers Program to include all carers, increased access to carer respite and time-limited support for those who are no longer carers.
- Support telephone, online and other accessible supports for carers, particularly regional and rural carers.
- Work with Aboriginal community-controlled organisations so that services can better support carers in Aboriginal communities.
- Include a focus in the Support for Carers Program for services to support Aboriginal carers, people in LGBTI communities and carers of culturally diverse backgrounds.
- Enhance the Mental Health Carer Support Program to improve statewide access to supports and system navigation for mental health carers.
- Explore opportunities to enhance mental health carer advocacy options, to uphold the principles in Victoria's *Mental Health Act 2014*.
- Implement the Office of the Chief Psychiatrist's *Family and carer guidelines*, which align with the principles in the Mental Health Act.
- Continue to work with the NDIA for greater support for people with a disability, their families and carers.
- Increase carer understanding about what support people in care relationships can receive through the NDIS, including through the ILC part of the scheme.
- Improve the 'Everything Carers' website, providing easy-to-find and easy-to-read information that supports carers and offers practical support.
- Promote the services and supports carers can use through other information sources such as the Better Health Channel and carers' support organisation websites.
- Support carers of culturally diverse backgrounds to access information in appropriate ways, such as through storyboards, and in relevant languages.
- Continue to implement community education through the '*Raising awareness of elder abuse in ethnic communities*' project, which helps people of culturally diverse backgrounds, including their carers and families, to be aware of elder abuse and how to access services and supports.
- Support Carers Victoria to produce resources for people in care relationships on preventing and responding to family violence.
- Explore existing and new options to centralise information about carers so that carers do not have to repeatedly tell their story.

'I am not in a caring relationship at all. Know me for who I am. I have given up my life to be a carer... I am a mother, I am a wife, I am a parent, I am a carer. My daughter is not a burden, but the burden of caring for her is.'

Consultation participant



Carers have less financial stress

Priority 4

Carers told us their care role affects their income and financial stability. They said they want greater financial support, financial counselling to help them manage money better, more discounts and subsidies for energy, internet and buying computers, especially in regional and rural areas, and housing support.

They want more information and greater support in accessing help to pay for household items and big bills, and housing support.

What will be different

- Victorian carers will have access to services and programs that support financial stability and housing support.
- Victorian carers will be aware of financial supports and subsidised transport options.

Priority actions

- Investigate options for enhancing the benefits of the Victorian Carer Card to identify potential ways to reduce everyday cost pressures experienced by carers.
- Continue to fund the Companion Card for people who need a carer with them to go to community events and activities.
- Inform carers about financial support that they can access through the Carer Payment and Carer Allowance, other Centrelink concession cards, Veterans' Affairs concession cards, the Victorian Seniors Card, the Victorian Carer Card and the Mental Health Carer Support Fund through the Better Health Channel, Seniors Online, Tandem and other organisations supporting carers.
- Inform carers about other supports they may be able to access, including Victorian concessions, discounts and services for households, legal advice, and exemptions for carers who have to temporarily relocate, other housing support and support for kinship, foster and permanent carers.
- Support carers to better understand the role of the NDIS in improving wellbeing and economic participation for people with a disability and their carers.
- Revise the Support for Carers Program to specify financial counselling as a support for carers.
- Advocate to the Commonwealth Government for fairer means testing of carers with superannuation funds.
- Promote the use of the Housing Options Finder to assist Victorian carers to understand their rights and pathways to social housing.
- Provide training to carer support organisations on housing options and access to a range of housing products and the referral pathways to access these for carers and the people they care for.
- Seek opportunities to work with Good Money outlets to support carers' financial stability.
- Examine ways in which carers' access to public transport can be enhanced.

Carers are recognised, acknowledged and respected

Priority 5

Carers told us they want to be recognised as individuals in their own right, and for the community to acknowledge and understand the role and rights of carers. They do not want to be stereotyped, excluded, or discriminated against.

They want to be acknowledged by service professionals and others for their knowledge and experience of the person they care for. They want to know that when service decisions are made, their needs are also taken into account.

Carers want to be heard by organisations and service providers when decisions are being made about the person they care for. They told us more needs to be done for organisations and service providers to understand this, and understand their responsibilities for carer involvement under the *Victorian Carers Recognition Act 2012*.

What will be different

- Victorian carers will be recognised, acknowledged and respected for the role they play.
- 'Hidden' carers will be encouraged to access support and services to meet their needs.
- Victorian carers will be listened to, respected and involved in decision making about services and programs for people they care for.

Priority actions

- Support a whole-of-community campaign that recognises carers, addresses stereotypes, promotes carer supports and services, and supports carers to voice their needs.
- Identify diverse carers such as Aboriginal, culturally diverse, LGBTI, older and younger carers in community campaigns to increase awareness of carers.
- Increase information about and for diverse carers including through the Better Health Channel, Seniors Online, Seniors Information Victoria, media for young carers and translated information through the Health Translations Directory.
- Update and distribute a *Victorian Carers Recognition Act 2012* information kit for community, human services and health providers including mental health services, organisations supporting carers and diverse carers themselves.
- Enhance and promote resources for community, human services and health services and practitioners (including mental health professionals) to better support carer identification, carer needs and carer involvement in services, treatment and care planning.
- Improve identification of young carers in education settings and provide greater support.
- Introduce to Victoria the National Mental Health Carer Experience Survey to collect feedback from carers for service improvement.

'I have a really great GP and he is 100 per cent supportive and includes me in everything. Even my mum's psychologist includes me in everything and we talk all the time, and it's really great they trust me and will actually listen to me.'

Consultation participant

Next steps

Starting now we will provide information to carers, organisations, other groups supporting carers and service providers about this strategy, and how it will support carers.

We will work with peak organisations, service providers and communities to carry out the actions in the strategy.

We will develop new program and service guidelines and update existing guidelines where necessary.

We will regularly seek feedback from carers about how effectively the strategy is being implemented, including specific information about actions and improvements in programs and services.

Monitoring and review

We will monitor and review our progress in implementing *Recognising and supporting Victoria's carers*.

Some of the key questions we will ask carers and service providers to guide our review of progress will be: how have carers been better acknowledged, recognised and involved in decision making about services and programs for the people they care for?

What opportunities have carers been able to access for their own health, wellbeing and social and peer support? How are school, study and work environments better supporting carers? Are services and supports better meeting carers' needs? How has carer financial stability been supported?

We will monitor and review data from various services to see what progress is being made as we introduce changes.

We will conduct annual forums to review the strategy implementation from July 2019. The Parliamentary Secretary for Carers will lead the forums. Given this is a whole-of-government strategy and approach to support carers, the forums will include representation from a number of Victorian government departments.

The forums will engage carers in decision making and monitoring. We will also seek feedback and advice in the forums from representatives of carer peak bodies and service providers.



