# PAEC Inquiry into the Victorian Government's response to the COVID-19 pandemic

DECEMBER 2020

Carers VIC
Australia

# ABOUT CARERS VICTORIA

Carers Victoria is the state-wide peak organisation representing people who provide care. We represent more than 703,300 family carers across Victoria, of whom 221,300 are primary carers – people caring for someone with a disability, mental illness, chronic health issue or an age-related condition.

A carer is a person who provides unpaid care and support to an older person. This may include assistance with physical and personal care, emotional support, household tasks, transport and communication. The term carer is **inclusive** of partners, family members and friends who are involved in the care of the older person.

People receiving care could be a parent, child, spouse/partner, grandparent, other relative or friend. Carers Victoria is a member of the National Network of Carers Associations. Carers Victoria is a non-profit association which relies on public and private sector support to fulfil its mission with and on behalf of carers.

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Carers Victoria acknowledges the traditional owners of this land and pays respect to elders both past and present.

# INTRODUCTION

Carers Victoria welcomes the opportunity to contribute to the Parliamentary Inquiry into the Victorian Government's response to the COVID-19 pandemic. We commend the Committee undertaking to review and report on:

1. the responses taken by the responses taken by the Victorian Government, including as part of the National Cabinet, to manage the COVID-19 pandemic and
2. any other matter related to the COVID-19 pandemic up to each reporting date of the Committee.

It is a banal truism the pandemic has changed Victorian society in profound ways. People have experienced disruption to basic routines and the significance of social connections and freedom to wellbeing has been augmented.

Carers Victoria acknowledges the Andrews Government has set down its budget to assist Victorians to repair and recover from long periods of lockdown, remote learning and working and social disconnection. We are particularly pleased the Government has committed funding to:

- $4.6m to support carers pursue education and employment opportunities including relief for carers to get assistance with their caring responsibilities while they study and during their placements and additional supervision and support.
- $868m to support the implementation of the interim recommendations of the Royal Commission into Victoria's Mental Health System.
- $7m for extra publicly funded autism assessments over the next four years.
- An additional $223.3m over four years to support Victorians with a disability who are ineligible for the NDIS including $5m to continue the Government's Intensive Support Team until 2022 and $41.9m for the Home and Community Care Program for Younger People.

We also note the commitment to build more social housing which will support people with care needs to age in place for longer periods.

The spending budgets are impressive and address some of the long-standing challenges faced by carers and people with care needs which have been identified in the Victorian whole-of-Government Carer Strategy 2018-22.

Notwithstanding these announcements, Carers Victoria is concerned the Government has not specifically addressed the needs which have emerged during the pandemic and those which will be with Victorians long after 2020 is a distant memory.

This submission will inform the Public Accounts and Estimates Committee of the specific challenges carers faced during the pandemic as individuals and members of care relationships. It will provide recommendations about carer services and improvements needed at the level of specific sites or services.

# ACHIEVING CARERS' REPAIR AND RECOVERY

Carers Victoria strongly believes to support carers after the COVID-19 pandemic and during any future widespread social and economic disruptions, the Government should adopt the following carer-centric engagement principles.

1. View all carers as important stakeholders in their own right – not just as supports to people with care needs,
2. Ensure Government messaging and websites include sections relating to status, process and support for carers,
3. Build into policy design an analysis of the impact of policies on carers and people in care relationships,
4. Include mitigation strategies to support all people in care relationships especially those with complex needs, and
5. Establish direct feedback mechanisms to ensure adjustments can be made to better reflect carers' needs.

# HOUSEHOLD VULNERABILITY

As governments responded to the pandemic by imposing restrictions on social and economic activity and access to face-to-face healthcare and education, carers faced significant demands on their time and resources.

Many carers support more than one person and must negotiate more than one service sector and providers within each.

Over 25 per cent of Victorian respondents to the 2020 National Carer Survey report caring for two or more people.

Demands on carers also increased because of poor service planning at a state and federal level and an over-emphasis on individual vulnerability to the virus. Many people decreased or entirely withdrew from disability and aged care services. Older mothers withdrew services from their adult children or children from their elders because they or someone else in the household has compromised immunity. These decisions were made without necessarily appreciating the full extent of their implications on the carer's own mental and physical wellbeing in the short or long term.

Over 80 per cent of Victorian respondents to the National Carer Survey reported they live with the person(s) for whom they care.

> *"The pandemic has severely impacted me - mentally and financially. I withdrew from my casual position at Woolworths (25 years ) as I feared mum would die if she contracted it. I also raise two teenagers one of whom has a diagnosed mental illness, and I suffer from depression and anxiety."*
>
> Respondent to the National Carer Survey

People in care relationships were not provided practical resources that could minimise infection transmission such as personal protective equipment (PPE) and broad testing criteria.

In-home testing was only introduced during Stage 4 restrictions. This responded to an important issue for carers who faced difficulty in attending a testing site for themselves or the person for whom they cared without putting either at more risk.

## Recommendations

- Increase availability of voluntary testing for vulnerable populations,
- Indefinitely extend testing at home program,
- Allow for direct requests for PPE to prioritise vulnerable populations, and
- Provide assistance to GP clinics to conduct outreach activities.

# YOUNG CARERS

The impact of the pandemic on young people has been devasting with disruptions to school, employment, social networks and extra-curricular activities.

Young carers are particularly vulnerable to the disruptions created by restrictions to social, economic and medical activity and the despair the higher rates of youth unemployment are likely to engender.

> Young carers provide significant levels of care to their immediate and extended family members.
>
> They can be as young as four years old and highly likely to experience lack of sleep, ongoing stress and mental health issues.

Research from the Australian Institute of Family Studies indicates that even without the disruptions caused by the pandemic, young carers are by year nine, one year behind the education standards of young people who do not have care responsibilities.[1]

Recent findings of research to investigate the impact of the pandemic-related shut-downs indicate strongly that young carers experienced additional challenges with remote learning compared to young people without caring responsibilities. Young carers experienced more pressure in their caring role as they were constantly at home. They were required to provide additional assistance to the person receiving care and were less able to connect with services and friends that support them.

However, it is also important to recognise remote learning may have given some carers a level of flexibility to combine their studies and caring role like never before.[2]

From their dual experiences of being young as well as their caring role, young carers are particularly at risk of mental illness. This is particularly concerning due to increased rates of mental illness being experienced by young people due to COVID-19. For example, data from the Victorian Agency for Health Information shows a 72 per cent increase compared with last year in the number of serious self-harm and suicidal-ideation presentations in emergency departments for those aged under-18 during the final six weeks of lockdown.[3]

## Recommendations

- Young carers are recognised as a priority cohort by the Department of Education
- Young carers are closely supported to identify their needs for flexible learning and tutoring
- Young carers are recognised as a priority cohort within initiatives targeting the mental health of young people.

In its submission to the Victorian Government's Youth Strategy, Carers Victoria has recommended the adoption of Young Carer Action Plans.

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1. Australian Institute of Family Studies Longitudinal Study of Australian Children.
2. Carers NSW: Young carers and COVID-19
3. Victorian Agency for Health Information

# DISRUPTIONS TO CARERS' ACCESS TO DIRECT AND INDIRECT RESPITE

Carers already face significant restrictions on their ability to direct their own time in ways that benefits their physical, mental, social and spiritual health. Often times, high-quality services for the person with care needs are a significant – if not primary – source of respite for carers.

The National Carer Survey 2020 asked about the time carers generally have to themselves, that is being able to pursue activities of their choice not related to caring responsibilities, work or to household and other chores. Most Victorian carers agreed they have limited opportunities to direct their own time and pursue meaningful and necessary activities.

| | % | |
|---|---|---|
| | Agree | Disagree |
| I never get time out from my caring responsibilities | 44.7 | 30.8 |
| I am able to take just enough time out from my caring responsibilities to keep going | 48.9 | 29.4 |
| I am able to take just enough time out from my caring responsibilities to keep on top of other responsibilities like chores | 45.7 | 30.6 |
| I am able to regularly take enough time out from my caring responsibilities to properly relax and recuperate | 19.6 | 60.8 |

Respite is a crucial support in sustaining carers and care relationships. It is recommended for both carer and care recipient to spend time separately, interact with others and develop relationships or skills. It may also be carers' only opportunity to address their own health needs.

The pandemic (and other emergencies such as bushfires and floods) disrupted the dominant paradigm of respite which relies on substitute support in home or access to residential aged care facilities for overnight or day stay options and overnight disability accommodation.

Fortunately, some carers benefitted from the creation of new carer service models. These were in part funded through the Victorian government's Support for Carers Program.

Some providers were able to connect with carers through regular phone calls, individual and group exercise sessions and social support or send care packages or activity packs relating to a theme or current community event like the AFL grand final or the Melbourne Cup.

However, other providers with limited experience or capacity in virtual service delivery or servicing people who are older, from culturally and linguistically diverse communities, or regional or rural areas, faced significant challenges in providing effective alternatives in a timely manner.

These services faced a shortage of new staff within the broader sector while others had to backfill existing positions when existing staff were required to self-isolate if they were experiencing any COVID-19 symptoms.

Quite often the increased demand for respite created by the closure of aged and disability day programs and specials schools could simply not be met. The impact on carers is difficult to determine and will be felt throughout society for years to come.

## Recommendation

### The Victorian Government to invest in robust carer services

The Victorian Government should further invest in designing robust carer services to alleviate the mental and physical impacts of the COVID-19 pandemic on carers and ensure care relationships are sustainable in the future.

An essential component of a redesigned Support for Carers Program should be outreach activities to support carers.

Victorian carers need services which can promptly and adequately adapt to disruptions to the availability of personal support workers in the aged and disability sectors in addition to remote learning. Without investing in learning from carers' experiences of the pandemic, they will continue to be vulnerable to ongoing physical and mental health issues which have been caused by disruptions to face-to-face medical care and restrictions to social and economic activity.

# RECOGNISING CARE RELATIONSHIPS TO PROMOTE SOCIAL CONNECTEDNESS AND WELLBEING.

Carers are at the heart of specialist and mainstream services including health, education, disability, aged care and mental health. They have a crucial role in connecting people with care needs to services and often undertake hidden labour to ensure things run smoothly.

Whilst Victorian legislation formally recognises the important role carers play and obliges some services to respect and include carers when planning or delivering services, the pandemic has demonstrated the Victorian government must do more to meaningfully recognise carers in a range of settings to avoid long term physical and mental health impacts for all parties to the care relationship.

## Carer attendance hospitals in emergency and palliative care situations

Attending appointments and assistance with health care is a common feature of many care relationships. Carers are crucial partners in healthcare and an under-recognised (and unpaid) dimension of the health industry in Victoria.

67 percent of Victorian respondents to the National Carer Survey reported they assist the person they care for with taking medication, injections, or wound care and communication such as reading, writing, helping the person articulate themselves in conversations.

Appointments conducted via digital means can alleviate the need to attend in person; however, it remains common that carers are present during the telehealth appointment particularly if the patient is unfamiliar with videoconferencing, has low literacy, is older or is from a culturally and linguistically diverse background.

Carers also provide invaluable assistance at the bedside. In busy wards or emergency departments, they are available to assist the patient when nurses and doctors cannot. Carers also support communication between patient and hospital staff.

Despite the importance of carers, one of the most distressing aspects of the Government's response to the pandemic has been visitation rules for carers in hospitals.

Many carers reported significant distress at arriving at hospital in emergency situations with the person for whom they care only to be told they were unable to enter even in situations where the patient had limited capacity for speech, short term memory loss or could become agitated in a hospital setting.

This is alarming given recent Royal Commissions into the aged care (Fed) and mental health (VIC) systems and the treatment of people with disability have repeatedly highlighted the poor outcomes for these cohorts when they enter these sites.

# Marion and Rick

Marion cares for her husband Rick who experiences short-term memory loss as the result of an acquired brain injury (ABI).

Marion regularly accompanies Rick to his medical appointments, however, in August 2020 she was refused entry to their local hospital when attending a pathology appointment. The staff member supervising entry cited government COVID-19 protocols.

Marion explained Rick's inability to find the pathology department on his own and when again refused entry she requested that a hospital staff member accompany him to and from his appointment. She was advised this was not possible. Marion then cancelled the appointment and they returned home together.

This situation caused great stress to Marion and Rick as well as delaying important medical treatment. Marion contacted Carers Victoria for assistance with confirming government policy on the issue and advocating for carers to be exempt from restricted entry to medical appointments.

Carers Victoria's Sector Leadership Team contacted DHHS on Marion's behalf who advised that carers were permitted to attend medical appointments where necessary and COVID-19 risks could be minimised. Government announcements or hospital websites did not clearly stipulate this.

Under these circumstances, Marion should have been able to accompany Rick.

Carers Victoria's advisers worked with Marion to develop strategies to prevent her facing the same situation. These included calling the hospital ahead of time to advise the situation, carrying her carers card and taking a letter from Rick's specialist indicating his need for support.

# Ruby and Sarah

*"Our grief is tenfold because of the way we were all treated"*

Ruby lives in Sydney and was the primary carer for her 25 year-old daughter Sarah who was recuperating in Melbourne from significant medical treatment she obtained overseas in March 2020. The quality of Sarah's initial recovery was significantly reduced because Ruby was unable to provide daily care and attend medical appointments because she was required to quarantine in Sydney for 14 days. By the time Ruby had completed the quarantine period and travelled to Melbourne, Sarah's condition had deteriorated so much she required hospitalisation.

This was the first of two hospital admissions between March and September. At the time of Sarah's her death on 2 September 2020, her brain function was effectively nil.

Despite the severity of Sarah's condition and information published on the hospital's website regarding criteria for face-to-face support, treating staff at the hospital gave Ruby inconsistent information about visitation, she was faced with the constant need to state her case to visit and granted sporadic access to support Sarah face-to-face .

Without her mother's regular oversight, nurses did not adequately monitor Sarah's condition and administer appropriate care such as medication, food intake and hydration. Medication and food were placed out of Sarah's reach. At one stage she called Ruby begging to "get out" after being left in a room with no food, water or tissues and "being left in own soil" for hours. Sarah lost 7 kilos during this time.

The level of difficulty Ruby faced in getting staff to adequately monitor Sarah placed her in a position of "feeling forced" to remove Sarah from the hospital and provide care herself.

At one time Sarah was admitted to the COVID-19 ward. This was made on the basis of a high temperature and in due course, she tested negative to COVID-19. Despite her severely compromised immunity, staff kept Sarah in the COVID-19 ward for an additional two weeks due to shortage of other beds. It was only due to Ruby's advocacy (which was stressful for Ruby to undertake) that Sarah was transferred out of the ward. In the meantime, Ruby was consistently denied access to Sarah when she was in ICU on grounds of COVID-19 infection.

Since her daughter's passing, Ruby has reflected on the care Sarah received and believes staff were "hiding under the umbrella of COVID-19" as the excuse for their lack of adequate care.

The hospital denied repeated requests for video calls when face-to-face access was denied and particularly when Sarah's condition deteriorated. Ruby repeatedly phoned the ward, but it kept ringing out.

Just before Sarah died, Ruby was told she was responding by squeezing the nurses' hand.

Now Ruby says "that should have been my hand".

The impact on Ruby has been immense. She continues to live with the anguish of her child dying alone, frightened and with no opportunity to say goodbye. "She didn't hear our voices".

Ruby has since been diagnosed with post-traumatic stress disorder (PTSD) and has experienced difficulty returning to work. Despite this hardship, Ruby is adamant that the Government must do things differently; she has written letters to the Premier and current Health Minister but is yet to receive an adequate response. Ruby approached Carers Victoria to have her family's story heard and specifically requested that it was included in this submission.

# Recommendations

1. Ensure all health services consistently implement government directives and guidelines.
2. Treating professionals to provide written documentation stating care recipient's need to be accompanied by carer. This should be recorded on patient file rather than carer having to constantly restate their case for access.
3. Direct health services to allow carers to remain with their family member on the condition they do not have symptoms of COVID-19 and follow strict hygiene protocols.
4. Support liaison between clinical nurse consultants, patients and family members to determine visitation options.
5. Provide mental health first aid to all parties in the care relationship where face-to-face visitation must be limited
6. Refer patients and carers to health service patient advocate to support liaison with medical staff.
7. Maintain a current list of internal and external carer support services such as Carers Victoria, the Carer Gateway and Health Complaints Commissioner.
8. Ensure carer representation at all meetings and important communications with patient when patient's cognitive capacity is compromised or at their request. If not in person, then facilitate video or speaker phone access.
9. Provide easy access to video technology to facilitate social connections with carer or other family members.

# RESIDENTIAL AGED CARE FACILITIES

Similar issues of resident 'lock-ins' were widely reported by carers of residents of aged care facilities, including younger adults with disability and people with dementia – effectively locked away for months from their partners, children, parents and grandchildren.

It is difficult to estimate the mental and physical health impacts of such restrictions on both residents and their families; however, it has since been reported residents who were denied to talk face to face with loved ones or have their hands have experienced accelerated symptoms of dementia.[4] It is likely many carers will experience complicated grief if they lost their loved one at a distance or they have since witnessed their mental and physical deterioration.

Closed environments pose a disproportionately higher risk to vulnerable residents especially when the workforce is under significant professional and personal pressure. Many witnesses to the Royal Commission into the Aged Care Quality and Safety reported that residential facilities with little public oversight are most vulnerable to poor practices and care of residents.

Carers Victoria contributed to the 'Industry Code for Visiting Residential Aged Care Homes during COVID-19', a collaboration led by the Council of the Aged (COTA) between 13 aged care peak bodies and consumer advocacy organisations.[5] The Code was intended to create a nationally consistent approach to ensure residents can receive visitors while minimising the risk of spreading COVID-19.

Despite this, many providers continued to place a low value on the wellbeing of residents and carers. This was reinforced by a lack of Government leadership in calling on providers to protect residents and staff with proportionate measures and effective risk management strategies.

> It is crucial to understand that not all residential aged care facilities in Melbourne refused face-to-face visitors even during Stage 4 restrictions .
>
> These humane providers instead opted for rational crisis management – continuously consulted with residents, families, staff and the local community to ensure the needs of residents were prioritised.
>
> These 'small miracles' were created with robust emergency management processes, involving organisational leaders, clinical experts and frontline staff.

### Recommendations

- The State Government collaborate with the Commonwealth Government to ensure quality and safeguard measures such as unannounced visits remain in place throughout periods of community lockdowns.
- The State Government disallow lockouts which are disproportionate to the risk of infection for the local area.

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4. Australian Broadcasting Corporation news
5. Council of the Aged Industry Code

# HOUSEHOLD VISITATION RULES

When household bubbles were introduced during Stage 4 restrictions after weeks of social isolation, those in care relationships with a parent, partner or adult child were not afforded the same flexibility to create a social bubble with another household with children.

This relates to the Government's use of the word 'dependent'. While adults are generally not considered dependent on one another especially in a way that resembles children's dependence on their parents, those adults with high and complex needs require significant attention and support. Without appropriate guidelines for these relationships, many carers remained at risk of significant social isolation.

> Over 70 per cent of Victorian respondents to the National Carer Survey the person(s) for whom they care could only be left for a few hours at a time.

## Michelle and her parents Janet and Philippe

Michelle is a single woman living in inner Melbourne. During Stage 4 restrictions imposed by the Victorian Government, Michelle was limited in contact with close friends within 5 kms of her home. Her parents Janet and Philippe live 12 kms away. Janet cares for Phillipe who has advanced dementia. During Stage 4 restrictions, Janet experienced significant isolation as her most regular contact was with Phillipe whose dementia is too advanced. When the Government allowed for households to form a bubble amongst 'singles', Janet and Michelle were told they could not visit one another because Janet was not considered a 'single' householder. The wellbeing of every individual in the household.

### Recommendation

- Household visitation guidelines should stipulate specific conditions for care relationships, especially for people with high or complex needs, to ensure carers are not at increased risk of social isolation.

# SPECIALIST DISABILITY SCHOOLS AND EMPLOYMENT SERVICES

Over 55 per cent of Victorian respondents to the National Carer Survey reported caring for their child or children with disability.

The closure of schools to children with disability was a sudden shift for which few parents were prepared. Carers Victoria received a number of calls and through carer welfare checks, parents of children with disabilities revealed they were struggling with remote learning and a decrease in out-of-home care options. Many parents were likely to be juggling remote working or sudden unemployment and increased caring responsibilities for other family members or friends. These experiences were also reflected in media reports.

The inequities which exist in the education system for students with disability were exacerbated by school closures. Remote learning for families of children with disability did not specifically address the behaviours of concern which some children can display when their routines and their social connections are disrupted. Using digital devices to deliver lessons could also contribute to behaviours of concern.

The closure of specialist disability schools during Victoria's 'first wave' of the pandemic significantly disrupted student's access to important therapeutic supports the National Disability Insurance Scheme is careful not to duplicate. In the absence of those school-based supports, these students are unlikely to have enough funds to cover the costs of individualised services.

Some employment services for people with disability also closed during Stage 4 restrictions. Unlike other disability services, these were not deemed 'essential' by DHHS. Yet, carers rely on these services as well. Carers Victoria was contacted by Farah whose 23 year old son Raji had no alternative services. This put Farah's job as a teacher at significant risk because once schools were reopened to all students and she was required to teach on site, there was no one to watch Raji at home despite his high needs.

> *"I don't believe specialist schools should have closed during Victoria's first wave. It meant my son completely disengaged from school. Then the school used the pandemic as an opportunity to deny his right to finish his education.*
>
> *They denied Franklin the opportunity to attend school during Stage 4 restrictions despite the fact he was entitled to do so.*
>
> *Two weeks after schools were reopened to all students, I had to call them to talk about his return.*
>
> *Between March and December, Franklin attended his school for two hours. It's heartbreaking and unfair."*
>
> Rosa

## Recommendations

- The Department of Education direct schools to genuinely engage with carers of children with disability to ensure their education is not compromised during community shutdowns.
- The Government provide additional resources for carers needing to work or study whilst remote learning is required, or services are shut
  - These supports to include financial support to take unpaid carers leave.

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This submission was prepared
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Rainbow Tick

Quality Innovation Performance
ACCREDITED

Carers Victoria acknowledges the traditional owners of this land and pays respect to elders both past and present.

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