

Mental Health Family Carer Experiences of COVID-19 in Australia

Final report for the National Mental
Health Commission from the
NMHCCF as part of the Pandemic
Grants for Priority Groups

Associate Professor Melissa Petrakis
Research Associate Caroline Walters
SWITCH Research Group, August 2022



Acknowledgement of Country

SWITCH Research Group and the National Mental Health Consumer and Carer Forum acknowledge the traditional custodians of the lands throughout Australia. We pay our respects to their clans, and to the elders, past present and emerging, and acknowledge their continuing connection to land, sea and community.

Lived Experience

We acknowledge the individual and collective expertise of those with a living or lived experience of mental health, alcohol and other drug issues. We recognise their vital contribution at all levels and value the courage of those who share this unique perspective for the purpose of learning and growing together to achieve better outcomes for all.

Suggested citation

Petrakis, M. and Walters, C. (2022). *Mental Health Family Carer Experiences of COVID-19 in Australia: Final report for the National Mental Health Commission from the NMHCCF as part of the Pandemic Grants for Priority Groups*. Melbourne: SWITCH Research Group, Monash University.

CONTENTS

Acknowledgement of Country	2
Lived Experience	2
Suggested citation	2
FIGURES.....	6
TABLES	6
ACKNOWLEDGMENTS.....	7
EXECUTIVE SUMMARY	8
PART 1 WHAT WE DID	11
INTRODUCTION TO PROJECT	11
Background.....	11
Purpose	11
Project Partnership with SWITCH Research Group	11
Phases of the project	12
What the research involved.....	12
Who was invited for this research	12
Consenting to participate in the project and withdrawing from the research	12
Benefits and challenges in participation	13
Confidentiality	13
Challenges in accessing a broad and diverse voice of mental health family carers	13
PART 2 WHAT WE HEARD.....	14
FOCUS GROUP - WHO WE HEARD FROM.....	14
FOCUS GROUP – WHAT WE HEARD.....	17
Concern about consumer experiences.....	17

Concerns about service provision	18
Diversity across the lifespan	19
Carer personal experiences	21
Increased levels of care provision	22
Complexity of care provision	23
Factors leading to beneficial experiences	25
Enhanced strategies and skills.....	27
Innovations provided that were or could be responsive to need	28
Implications for policy and practice	29
Impact of system failure/ challenges on family and carer	30
SURVEY – WHO WE HEARD FROM	33
SURVEY – WHAT WE HEARD	34
Increasing levels of care	35
DEMAND AND COMPLEXITY OF SUPPORT	35
Complexity of support and care.....	37
Increased understanding.....	42
LEVELS OF STRESS EXPERIENCED.....	42
Suicidality – suicide prevention service responses for family members	44
Domestic Violence	45
Family unit distress	47
Severe and persistent fatigue.....	47
Own health and social challenges.....	47
Exclusion from service settings and treatment decision making	50
Navigation needs through peer navigation	51
Respite	52
Mobile centre response – disaster (impossible to get to help)	52

teleHealth	52
Older carer fears/ if unwell	53
Beneficial innovations for family carers	53
PART 3 WHAT NEEDS TO HAPPEN	54
SITUATION INTERNATIONALLY AND PRIOR TO COVID-19	54
SUMMARY OF WHAT WAS HEARD.....	55
Focus groups	55
Survey	55
Diversity of voices	55
CONTEXT IN RELATION TO THE PRODUCTIVITY COMMISSION	55
RECOMMENDATIONS	58
REFERENCES	59
APPENDIX A TERMS OF REFERENCE	61
APPENDIX B FOCUS GROUP PROTOCOL.....	64
APPENDIX C SAFE SHARING	66
APPENDIX D ETHICS APPROVAL LETTER.....	68

FIGURES

Figure 1 State of focus group participants	14
Figure 2 Gender of focus group participants	14
Figure 3 Focus participant age in 5 years groupings	14
Figure 4 Focus group participant self-identity	15
Figure 5 Identity of the supported person	15
Figure 6 Relationship of supported person to carer	16
Figure 7 Living arrangement of the supported person	16
Figure 8 State of survey respondents	33
Figure 9 Survey respondent's geographical area	33
Figure 10 Survey respondent's gender	33
Figure 11 Survey respondents age in 5 years groupings	33
Figure 12 Identity of family carer	34
Figure 13 Years of support provision	35
Figure 14 Living arrangement of supported person	36
Figure 15 Impact of loss of consumer services	37
Figure 16 Identity of supported person	38
Figure 17 Conditions of supported persons	38
Figure 18 Mental health challenges of supported person	39
Figure 19 Worry about getting sick and not being able to provide support and care	53
Figure 20 Sharing your story safely	66

TABLES

Table 1 Relationship of supported people	35
Table 2 Stress of COVID related impacts	40
Table 3 Activities of support during COVID	41
Table 4 Period of pandemic when most stressed	43
Table 5 COVID-19 related stressors	44
Table 6 Experiences of domestic violence	46
Table 7 Family carers personal health and social challenges	48

ACKNOWLEDGMENTS

We would like to acknowledge and thank the family and supporters from the following organisations, who gave their time to co-produce the process, participate in the collection and analysis of the data, and willingly shared their experiences to enable the production of this report.

Project Steering Group

Organisation	Representative
NMHCCF	Eileen McDonald (Chair)
NMHCCF	Kerry Hawkins
NMHCCF	Hayley Solich
NMHCCF	Sharon Lawn
NMHCCF	Carli Sheers
Mental Health Australia	JulieAnne Anderson
Mental Health Australia	Emma Coughlan
National Rural Health Alliance	Gabrielle O’Kane
MIND Australia	Nicola Ballenden
Mental Illness Fellowship of Australia	Tony Stevenson
National Mental Health Commission	Rachel Earl
	Isabella Bishop
National PHN Mental Health Lived Experience Engagement Network (MHLEEN)	Lynda Watts
Embrace Multicultural Mental Health	Nevena Simic
The National Aboriginal and Torres Strait Islander Lived Experience Centre – Black Dog Institute	Vicki McKenna
Mental Health Family and Friends Tasmania	Maxine Griffiths and Glen O’Keefe
Arafmi, Queensland	Alex Tyson and Ben Tisserand
Helping Minds, WA	Danielle Moore
Tandem, VIC	Amaya Alvarez
Mental Health Carers NSW	Jonathon Harms
Mental Health Carers Australia	Katrina Armstrong

We acknowledge the family carer participants both within the focus groups and who responded to the survey, for their time wisdom and experience.

The National Mental Health Commission, has funded this research to understand the experiences of mental health family carers and therefore provided an opportunity for mental health system improvement and reform.

EXECUTIVE SUMMARY

Summary

This research project found the COVID-19 pandemic increased the level and complexity of support provided by mental health family carers. The closure and restrictions on services led to family, carers and supporters needing to provide extra hours and at times constant support, including maintaining the safety of the consumer through monitoring both emotional and physical needs. Many families spoke of the challenges of providing support within community and service restrictions and across borders. The impact of these burdens arising through systemic failures led to isolation, feelings of being overwhelmed, physical and emotional distress and reported thoughts of suicide. The COVID-19 pandemic highlighted prior areas of systemic support that had been missing and also the loss of services that had been of benefit to the consumer and family supporters.

The National Mental Health Consumer Carer Forum (NMHCCF) engaged **SWITCH Research Group, Monash University** as the research partner to work with the Project Steering Group to co-design and co-produce data gathering and data analysis, including: development of tools; preparation of project resources; data gathering and analysis; and with the preparation of the final report. Through state focus groups and a national survey, the researchers investigated the significant adverse impact on mental health carers, their overall experiences, levels of distress, unmet needs and their caring responsibilities due to and during the COVID-19 pandemic.

Recommendations

The following recommendations have been developed through the voices and experiences of families which have been adversely impacted by the COVID-19 pandemic, but also speak of difficulties experienced through services not engaging with them or lack of systemic support in helping them to maintain a quality of life within their family and society/community. The 10 recommendations include 5 in the short term which could be actioned in 6 to 12 months. However, many of the recommendations echo and extend calls for change documented in previous policy documents including the *A National Framework for Recovery-oriented mental health services* (Department of Health and Ageing, 2013) and the more recent *Mental Health, Report no. 95* (Productivity Commission, 2020).

Short term

1. Australian governments to review practices in inpatient and other clinical settings to ensure family inclusion and partnership in supporting people with mental health challenges.
2. Australian governments to fund the creation of carer peer navigator roles – providing information and support – across inpatient and community services for families, carers and supporters.
3. Australian governments to prioritise the creation of carer support on-call roles, accessible via local and regional mental health triage services, to respond to crises experienced by families.
4. The Australian Government to fund available and responsive mental health carer respite to ensure carer workload does not overwhelm family members so they are able to remain in paid work.
5. In order to respond to current and future major disasters (pandemics, fires, floods, and drought), Australian governments to create local and regional mobile centres for family assistance.

Long term

1. The Australian Government funds diverse modalities of consultations and therapeutic interventions to enable mental health consumer and carer choice, inclusive of but not defaulting to teleHealth.

2. The Australian Government, in recognising the risk inherent in providing long-term and acute mental health care on carers, to establish domestic violence services tailored and responsive to family members experiencing acute and/or cumulative risk and violence.
3. The Australian Government, in recognising the impact of providing long-term and acute mental health care on the psychosocial wellbeing of carers, to establish suicide prevention services responsive to family members experiencing acute and/or cumulative stress and distress.
4. The Australian Government to establish funded family-carer collaborative hubs to foster, mentor and disseminate family leadership in service redesign, evaluation and research.
5. The Australian Government to provide national guidance and co-ordination for innovation across all states in administration and guardianship as it relates to mental health carers concerned about the safety of loved ones in their absence or upon their death.

What our research is about and why it is important

During the Covid-19 pandemic, one vulnerable population group identified in the National Mental Health Pandemic Plan was informal/unpaid carers. There are more than 240,000 people in Australia who are informal/unpaid mental health carers. Carers are known to have poorer mental health than the general population and the Pandemic exacerbated this. In June 2021 the National Mental Health Commission (the Commission) funded ten projects investigating the impact of the COVID-19 Pandemic on different communities in Australia. This project was selected as part of that process to investigate how the COVID-19 pandemic impacted the mental health and wellbeing of mental health family, carers and supporters.

In Australia, (Diminic et al., 2019) published 'A profile of Australian mental health carers, their caring role and service needs: results from the 2012 Survey of Disability, Ageing and Carers'. Results were: In 2012, there were 225,421 co-resident carers of adults with mental illness in Australia, representing 1.0% of the population, and an estimated further 103,813 mental health carers not living with the care recipient. The majority of co-resident carers supported one person with mental illness, usually their partner or adult child. Mental health carers were more likely than physical health carers to provide emotional support (68.1% v. 19.7% of carers). Many primary mental health carers (37.8%) provided more than 40 hours of care per week. Only 23.8% of primary mental health carers received government income support for carers and only 34.4% received formal service assistance in their caring role, while 49.0% wanted more support. Significantly more primary mental health than primary physical health carers were dissatisfied with received services (20.0% v. 3.2%), and 35.0% did not know what services were available to them.

What did we want to find out?

The research objectives of the project were to:

- Gather evidence on the impact of the Covid-19 pandemic on levels of mental health carer distress in Australia
- Identify Australian mental health carer unmet needs arising from the Covid-19 pandemic.

What did we do?

The researchers engaged with mental health family carer organisations and individuals in every state and territory. Additionally, spoke with priority populations of young people, aging people, LGBTQI+ community, Aboriginal and Torres Strait Islander people, CALD communities, veterans alongside people who could speak to the impacts of supporting people who experience AOD use, suicidal behaviour, and justice system challenges. National Project Steering Group participated in 6 cycles of codesign: engagement; literature review; co-design of focus group protocol and national survey instrument; data collection; interpretation of results; and preparation of final report and dissemination strategy.

What did we find out?

- Family carers reported there were repeated if not routine breaches of family carer rights to access treatment and support for themselves and their unwell family members during the COVID-19 pandemic and access was worse than usual
- Rigid adherence to inconsistent and changeable health directions resulted in high levels of family carer distress and powerlessness over the prolonged period of the pandemics (more than 2 years)
- Family felt invisible and broken during the COVID-19 pandemic by the deepening of existing exclusion from clinical care planning – the value of a sense of connection was highlighted and emphasised as a preferred way to be treated
- Despite challenges experienced many families utilised restrictions on movement and activities to connect deeply with household and community members
- Government policy and pandemic responses were predicated on an unjust assumption that family members would, without financial, practical or emotional resources, fulfil the role of care provision and support to unwell and extremely distressed people with new or ongoing mental and psychological ill health.

Opportunities from our research

This project demonstrated the capacity of the NMHCCF to co-lead, co-develop research and the value of findings which authentically include family carer voice and experiences.

This project demonstrated the capability of SWITCH research group – and more specifically – Melissa Petrakis and Caroline Walters – to mentor co-design and co-produce lived and living experience research immersed in family carer and consumer expertise.

Contact us:

- National Mental Health Consumer and Carer Forum – Website: <https://nmhccf.org.au/> Email: nmhccf@mhaustralia.org
- SWITCH Research Group, Monash University – Website: <https://www.monash.edu/medicine/spahc/socialwork/research/switch-research-group> Email: melissa.petrakis@monash.edu and caroline.walters@monash.edu

PART 1 WHAT WE DID

INTRODUCTION TO PROJECT

Background

A report commissioned to explore the wellbeing of informal carers identified they had the lowest wellbeing of all groups within an Australian National study (Weinberg & Cummins, 2015). The study indicated that care provision takes a “deep toll on the subjective wellbeing of carers” (Weinberg & Cummins, 2015, p. 621) and therefore highlights the need for more support for the wellbeing of those who provide care. The distribution of depression was also seen as higher amongst carers compared to the general population with more than 50% of carers scored in the depressed range compared to only 6 % within the general Australian population (Weinberg & Cummins, 2015, p. 622).

Caregivers in general have experienced increased stress, and international studies have noted that family distress is higher in families of people who experience mental health challenges or psychological distress (Fusar-Poli et al., 2021).

From its inception, this project has been designed and produced with mental health family carers and consumers based on their expertise in understanding their experiences and ways to best explore these to the benefit and wellbeing of family carers. Co-production in research, which includes people at the heart of the research interest, has distinct advantages in creating more appropriate recruiting, the ability to empathise with the experiences of participants and ensuring the process and content are meaningful and supportive (Simblett et al., 2021).

The terms family, family carer, carer and caregiver are used interchangeably throughout this report as they all appear in the literature, policy documents, and the data collected in this project.

Purpose

The aim of this research was to gain an understanding of the experiences and wellbeing of family carers who provided support to people with mental health challenges during the COVID-19 pandemic.

Project Partnership with SWITCH Research Group

The National Mental Health Consumer and Carer Forum commissioned the Social Work Innovation, Transformation and Collaboration in Health (SWITCH) Research Group located within Monash University, Faculty of Medicine, Nursing and Health Sciences to undertake this research. The Group Director is Dr Melissa Petrakis, Associate Professor in the Department of Social Work, School of Primary and Allied Health Care (SPAHC), at Caulfield Campus. The research group brings together 12 industry-partnership research studies, being carried out over the next 5 years led by Chief Investigator Dr Melissa Petrakis. The studies include exceptional practice-based research in health and mental health services and sectors, including Senior Clinician co-researchers and partnership organisations.

The project was established through a co-production process between SWITCH and the project steering group consisting of members from organisations across Australia and listed in the project steering group table within acknowledgements.

Phases of the project

1. Establishing co-production framework and project steering group
2. Co-design process and ethics approval
3. Data gathering: Focus groups
4. Data gathering: Survey
5. Data analysis and determination of findings
6. Co-reflection and establishment of recommendations

What the research involved

The aim of this study was to work with family, friends, carers and supporters of people with mental health challenges, mental illness or psychological distress to understand their experiences especially in relation to the impact of COVID-19 on their caring responsibilities, unmet needs and levels of distress. Family within this study encompassed all people in a significant relationship with a mental health service user, including family of origin, family of procreation, or family of choice.

The research project was co-designed with a project steering group composed of family carers and consumers representing the National Mental Health Consumer Carer Forum and the peak bodies for family carers across Australia. The project involved two studies, and participants were invited to take part in one or both and they could choose to take part in one or both.

1: Survey In this study participants were invited to complete an anonymous survey about their experiences as a family carer during the COVID-19 pandemic. The survey took between 20 to 40 minutes to complete depending on the level of detail provided. The survey was anonymous. It collected demographic information about carers, their support role and the person they support (with an ability to choose which questions they wanted to answer). Participants are not able to be identified and any reports or

publications generated will only refer to pooled data. The survey had set response and open-ended questions for people to answer. At the end of the survey participants could opt in to a draw for 3 vouchers of \$100 as appreciation for participation.

2: Focus Groups In this study participants were invited to attend a focus group, which was conducted online due to ongoing COVID-19 restrictions and new variant outbreaks. The focus group ran for approximately one and a half hours. The focus groups were recorded to assist with analysis. Participants in the focus group received a voucher for \$50 in recognition of their time and expertise.

Who was invited for this research

Participants were invited to take part because they were a family, friend, carer or supporter of a person with mental health challenges, mental illness and/or psychological distress. Some participants were invited as they were currently a member of a family support network who was working with this project or they may have answered an advertisement about the project.

Consenting to participate in the project and withdrawing from the research

Participation in this research was voluntary. We encouraged people to read the information in the explanatory statement, and if they had any questions to ask the researchers nominated at the top of the statement. Completion of the survey indicated consent to participate. Participants were free to withdraw at any time. However, it was not possible for information to be identified and removed, once a person had submitted the survey. If a person participated in a focus group, they were free to leave at any time, without question. Similarly, the information gained within focus groups was pooled data and it

was not possible to remove data up until the point of leaving a focus group.

Benefits and challenges in participation

Participants gained the opportunity to meet with other families and share experiences, which was noted by many as beneficial. Further, gaining a greater understanding of the experiences of family, friends, carers and supporters, provided benefits through advocacy and raising awareness of needs, as well as informing the development of programs and services to support family carers.

Completing the survey or attending a focus group was unlikely to cause any discomfort, and none were reported. However, measures were taken to provide support during focus groups and the explanatory statement form provided to each participant outlined freely available services people could contact.

Confidentiality

No information that participants gave was revealed to another person in any form which identified them. The survey completed did not include names, so it was not possible for the survey data to be linked to a person. If participants chose to enter the draw, their name was held separately from the other data and was destroyed once the draw occurred.

The focus groups were recorded and the recordings transcribed. Participants within focus groups were asked to maintain

confidentiality and to not repeat information that was revealed within the group unless given permission. Any identifying information, such as names spoken within the group, were removed from the transcriptions. Participants were made aware that a report of the study would be compiled for the National Mental Health Commission, and may be submitted for publication, and/or used in conference presentations, but individual participants won't be identifiable in such methods of dissemination.

Challenges in accessing a broad and diverse voice of mental health family carers

The aim of the project was to reach a breadth and depth of voices of people family carers who support people with mental health challenges. A number of challenges impacted this including the urgency and time frame for the study to be completed within.

Two states where focus group numbers and responses to the survey were low were experiencing challenges during this time including Queensland were experiencing floods and the Northern Territory were entering their first episode of COVID-19 presence. An indigenous-specific focus group will occur in second half of 2022, to allow for co-development of the process.

Alongside this some families were most likely unable to find time outside of supporting loved ones during the period of the study.

PART 2 WHAT WE HEARD

FOCUS GROUP - WHO WE HEARD FROM

Seven focus groups occurred online, in April 2022, via the Zoom platform in the states of Queensland, New South Wales, the Australian Capital Territory, Victoria, South Australia, Western Australia and through the National forum for Embrace multicultural mental health (Figure 1).

Seventy-three people participated in the focus groups. The majority of participants identified as female (Figure 2) and ages ranged from 21 to 80 years of age (Figure 3), with the average age being 56 years.

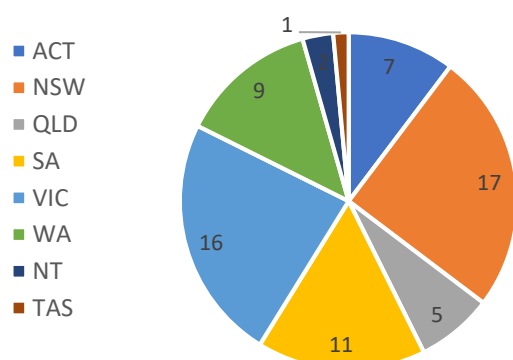


Figure 1 State of focus group participants

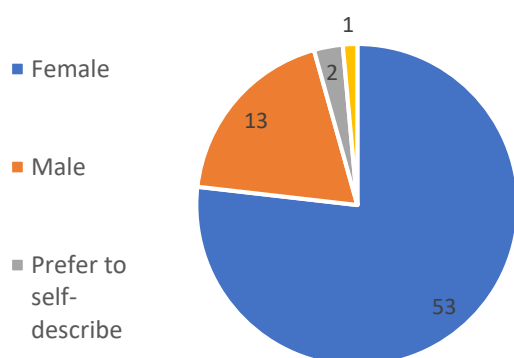


Figure 2 Gender of focus group participants

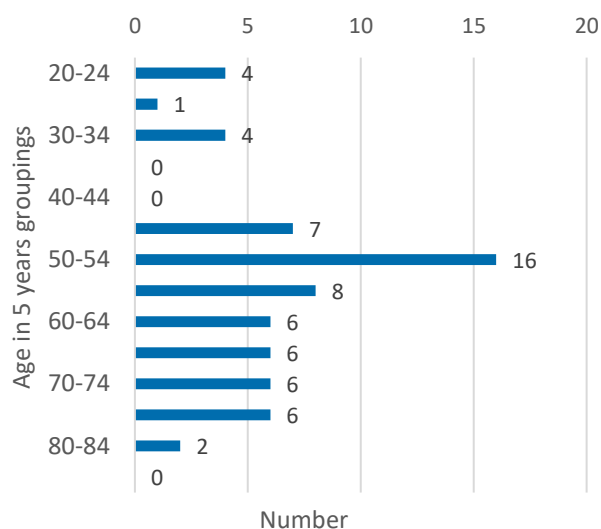


Figure 3 Focus participant age in 5 years groupings

Focus group participants self-identified as representing a diversity of communities for both themselves (Figure 4) and the people they supported (Figure 5). These diverse communities identified experiences that were both similar but also nuanced. Of note are the number of family carers who also identified as consumers (23).

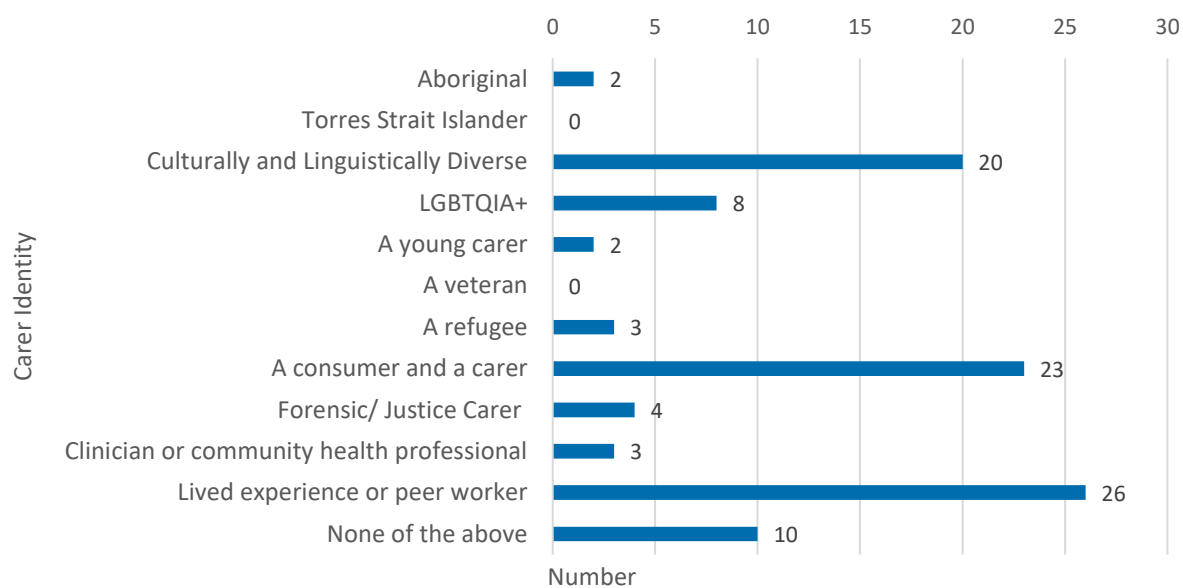


Figure 4 Focus group participant self-identity

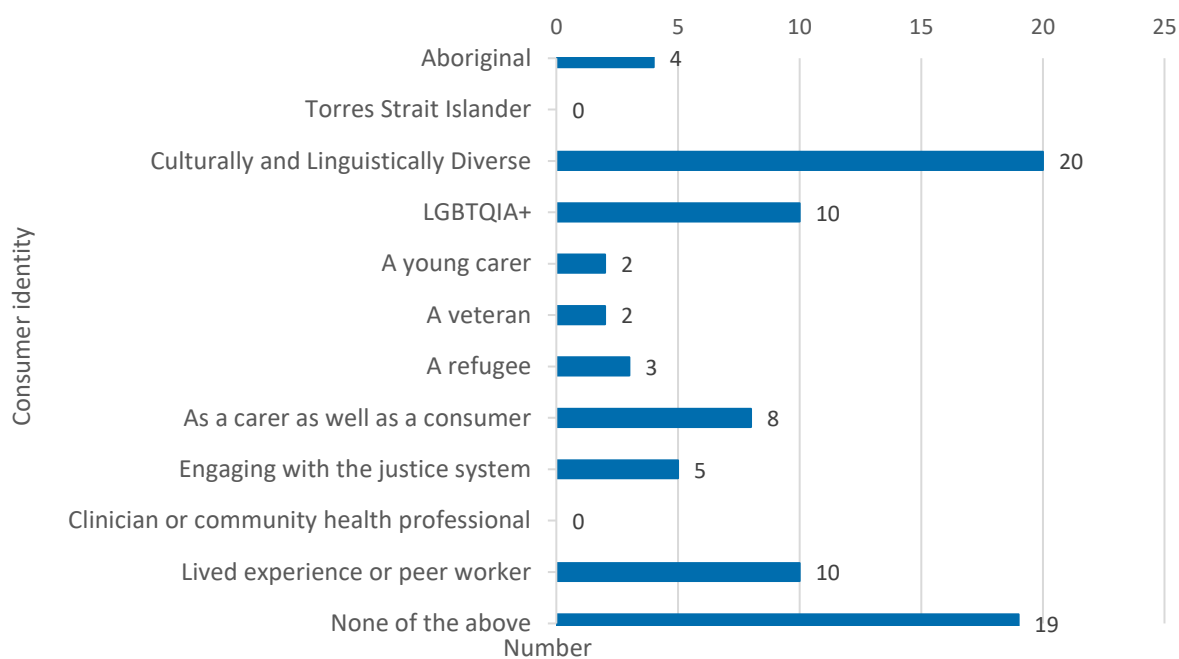


Figure 5 Identity of the supported person

There was diversity across the relationships and ages of people supported (Figure 6), however the majority (24) of participants

were parents and the majority (27) of family carers lived with the person they supported prior to and during the pandemic (Figure 7).

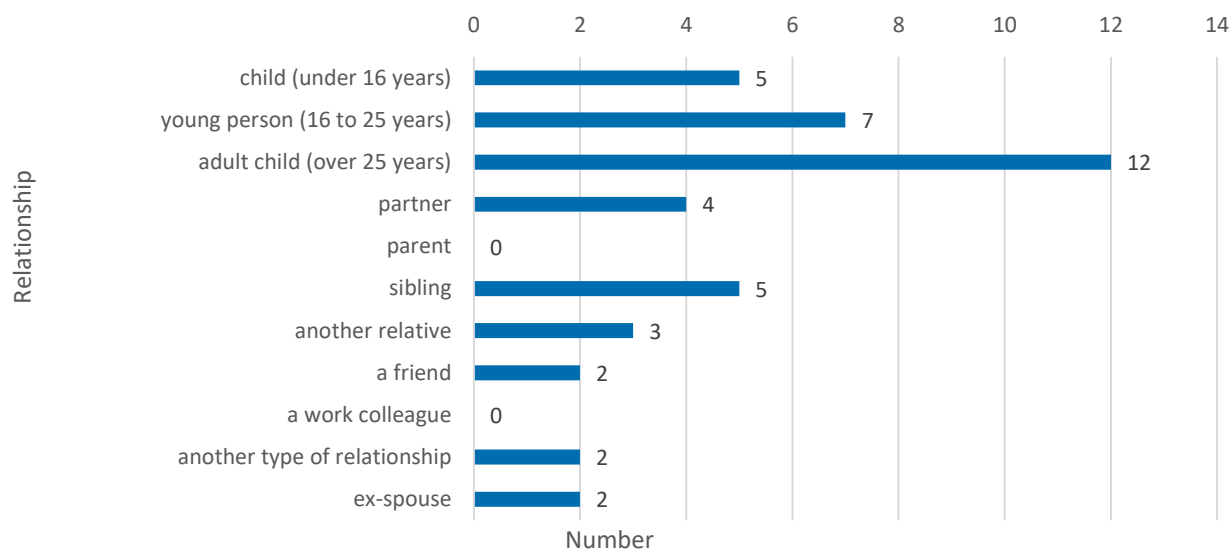


Figure 6 Relationship of supported person to carer

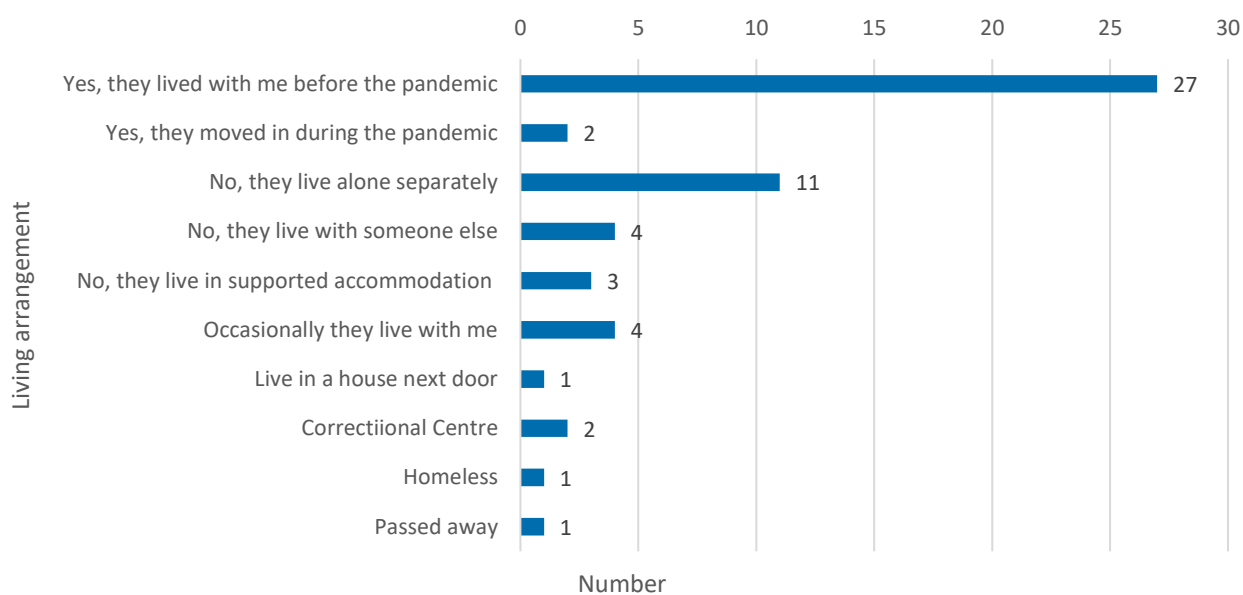


Figure 7 Living arrangement of the supported person

FOCUS GROUP – WHAT WE HEARD

Through the focus groups we heard, that during COVID-19, services operated on reduced hours, closed completely or changed to modes of practice that did not suit people with mental health challenges and psychosocial distress. These experiences contributed to feelings of being overwhelmed, of distress and fear, and increased burden in family members.

For some carers this was their first experience of this level of mental health distress and needing to access supports, for others these circumstances exacerbated pre-existing demands and difficulties in accessing care and support for loved ones and in their own right.

Suggestions and solutions from carers varied some of which were according to age, life stage, cultural identity, gender and multiplicity of caring responsibilities, and own health needs and challenges.

Concern about consumer experiences

The experiences of the consumer that are of concern to the family carer

- Increase in psychological distress and symptoms
- Closure of usual activities
- Services closed

Many of the experiences for consumers arising from the impact of COVID-19 were of concern to family and carers. These included personal losses the consumer experienced that often arose through the 'new normal' of restrictions, which included the closure of

usual activities that provide purpose and connection, loss of ways of self-managing, such as going out for walks or bike rides and loss of employment.

These losses resulted in decreased sense of purpose, social isolation and financial concerns for the consumer. Alongside these experiences all family participants reported the person they supported 'losing' services, having service frequency reduced or service modes changed to options that were unacceptable or unable to be engaged with. They reported the consumer feeling abandoned especially when disconnection was from known and valued services or workers.

The loss of services also resulted in reduced monitoring for symptoms and access to medications. Participants identified in a number of cases extreme consequences arising from the loss of services including consumers receiving custodial sentences and being placed in prison.

Consumers also experienced heightened psychological distress and symptoms from expressed anxiety of fear of catching COVID-19, restrictions around attending hospital, including not being able to have a support person when going to emergency departments and participants especially within culturally and linguistically diverse (CALD) communities noting increased suicidal behaviours within their communities.

Participants were grateful for and also curious about the types of services that did continue which included support people who provided cleaning services and 'meals on wheels'. Participants wondered why these support people were able to attend when others who provided therapeutic services could not.

When restrictions eased, participants reported consumers experiencing difficulties reengaging with services and socially. These

difficulties included not wanting to participate in activities that they had previously enjoyed, feeling awkward in social situations which they had mastered prior to the pandemic and therefore an ongoing experience of social isolation was occurring.

“ Now that services are coming back and face to face is coming back He, he doesn't want to leave the house, he doesn't want to have people come into the house. So, it's still me doing the whole lot 24/7 (New South Wales, Mother).

”

Concerns about service provision

Concerns expressed by family or carers about service provision during COVID-19

- Sudden closures of services
- Family blocked from active engagement
- Rigid and inconsistent applications of rules and visitation practices

Mental health services were under pressure to understand and manage the new and evolving restrictions arising from the COVID-19 pandemic. Participants expressed concerns about a number of areas of service provision including the sudden closures of services through restrictions which left consumers doubly disadvantaged when family could also not travel to provide support.

Changes in staffing, in response to safety and illness, meant a loss of continuity of care which was identified as particularly problematic within NDIS service provision as much of this work is within the realm of social prescribing and support, meaning the benefit is through known built-up relationships.

COVID-19 restrictions created increased challenges in consumers gaining entry to services. When emergency services were called family experienced a lack of engagement with them, and rules restricted family attending with the consumer at emergency departments. Participants also identified the threshold for entry for hospital admissions appeared higher than pre-COVID, with the consumer reporting a number of times to emergency departments but being discharged home, even when they expressed thoughts of suicide.

“ The impacts, I guess, if I'm thinking back, mostly was around the doctor and psychologist appointments, it was really difficult to obtain them. And often, you know, if you did obtain an appointment, it had to be over the phone; which wasn't ideal for my son, or for myself. And I found the extra level of distress my son experience impacted on the support that I needed. So, services were at capacity: hospital was overwhelmed. My son made, you know, five serious attempts on his life through that period. So COVID (was hard) because he was just constantly sent home and felt unsupported. (Queensland, mother)

”

Many concerns were expressed by participants around engaging with services, especially around the policies, rules, and restrictions enacted in responding to the pandemic. Participants experienced rigid and inconsistent applications of rules particularly around visitation practices. It was recognised that the workforce had reduced numbers and were experiencing burnout, and this may have impacted the approach of individual providers.

“ I'm not allowed in the treatment area that I was allowed to stay in before when I support him; now I can't even go in there because I'm not allowed to stay with him because you know all the vulnerable people there...so sometimes I just stay in the car... So instead of going home, to save myself you know petrol money, I'll just stay in the car sometimes say for like four hours; five hours, wait for him in waiting for them to ring me to say he's ready to be picked up. So that's really the impact on him and me as well because of the restriction that the COVID has brought (ACT, Wife). ”

Some participants expressed concerns over the approach of workers towards the consumer and themselves, with some feeling there was a lack of care or concern for the consumer or carer, with no follow-up when family expressed dire need, nor attempts by service providers to actively engage with consumers who wanted to opt-out.

A number of families spoke of supporting people within the justice system and visitation restrictions were tight, requiring people to strongly advocate to have allowances to visit when they were restricted and yet external workers could attend. The inconsistency or rigidity of rules created distress for both the consumer and family. The inability to visit and the move to telephone or online meetings was seen as adding to the challenges of family being included and understanding how to provide support. Family also felt services didn't initiate reaching out to them.

A number of concerns were raised regarding discharge practices during COVID-19. One participant described their daughter being discharged into the car park. Telephone follow-up by services in this case was *pushing the narrative of has she taken her meds.*

Diversity across the lifespan

Diverse experiences through differences across the lifespan

- Young carers had difficulty accessing free/ low-cost services
- CALD carers wanted more holistic models of care, and reduced discrimination
- Regional and rural carers had poor access to psychiatrists and psychologists, with prohibitive costs and waiting lists

A number of unique experiences were expressed by family carers through diversity and differences across the lifespan. These

differences were experienced through diverse cultural backgrounds, different ages and developmental factors, gender diversity and geographic regions.

Young carers expressed difficulty accessing free or low-cost services, experienced challenges with mixing support responsibilities with education, and also high degrees of social isolation when unable to attend school or university. Similarly, supporters of young people expressed concerns about what young people have missed out on and the long-term impact of missed opportunities.

Representatives from CALD communities felt unable to fulfil many of their responsibilities to their community and also were unable to rely on their community for support, creating added dimensions of stress and difficulties.

Representatives of the CALD community also expressed experiencing difficulties accessing Centrelink and Medicare and other financial supports, especially international students. Some members expressed discrimination and racism, especially at the beginning of the pandemic.

CALD representatives wanted more holistic models of care with considerations of unique stories, including practices that are trauma informed, and understanding of underlying causes of distress.

Many noted the COVID-19 restrictions were triggering of trauma and that they had family members who they were concerned about and supporting in other countries.

Participants residing in geographic areas outside the main capital cities of Melbourne, Sydney, and Brisbane, spoke of the difficulties of finding service providers including psychiatrists and psychologists. If psychiatrists, psychologist and private services were available, the costs of services were found to be prohibitive or the waiting lists exceptionally long.

Many participants expressed their concerns about who would support their family member if they became unwell. This was especially apparent in older carers who expressed a desire for their family members to have an ongoing connection with a person in their life. They wanted someone who would understand the supported person, and their wants, needs and goals.

“ One really, really good thing that I would like to see in the future is for somebody to take a personal interest in our sons. Because when we got the NDIS, we felt Oh, hooray, everything will be fine. It'll all be just taken care of. But it's not quite like that. It does require somebody who really cares, overseeing what is going on. Because people with depression and anxiety and apathy and paranoia, they really need somebody from outside, helping them along (South Australian, Father). ”

Carer personal experiences

The stress, depression, anxiety, feelings of suicide, and losses experienced by family, and carers, alongside positive experiences

- A 'shrunk world' during COVID with a sense of loss of normal
- Loss of work and activities to fulfil additional support requirements
- Relentlessness of caring and a sense of hopelessness, with for some suicidality

Family explored their personal stress, depression, anxiety, feelings of suicide and losses experienced, alongside positive experiences. Family described an adversely affected, changed life, with increased personal mental health challenges.

Participants spoke of a 'shrunk world' where limitations formed during the COVID-19 pandemic had become habits, and that this had been a loss of a sense of normal. They also spoke of a sense of loss, from meeting caring expectations, around work or other activities they had to give up to fulfil additional requirements of providing support. This sense of loss included wanting to be in their relational role rather than the carer role –

“ And where's my meaning and purpose outside being a carer? And when do I get to be a mum? (Western Australia, Mother). ”

Participants expressed confusion and concern about the rules and reported either having to break the law to provide support or finding creative ways to work around them. Increased incidences of family violence, both of themselves but also within their communities, was reported.

Participants spoke of the challenge of working or studying from home and how this both assisted with providing support but also blurred the lines. Many who saw leaving home to attend work, or school, as respite once again experienced a sense of loss and an increase in the relentlessness of providing support.

Those who were able to change to working from home expressed some financial benefits. Participants also appreciated extra COVID-19 payments from the Government for themselves and the people they support, although some expressed being shocked when they received a tax bill arising from COVID-19 related payments.

Most participants spoke of their own mental health challenges, they experienced anxiety around COVID-19, about becoming unwell, and for those older carers, possibly dying. This eventuality raised concerns about who would look after the person they support.

Many spoke of the relentlessness of caring and a sense of hopelessness. Of feeling invisible and being exhausted and overwhelmed by the emotional and physical work of caring. Some spoke of a breaking point –

“ I feel like the pandemic did, you know, it didn't kill me, but it certainly broke me. (Victorian, Mother). ”

Some participants spoke of resorting to maladaptive coping techniques, including the overuse of alcohol and excessive eating.

Trauma was expressed from observing care practices and being an outsider witnessing the supported person's struggles. Those people who worked in family support roles expressed witnessing the distress of carers/family they worked with, which was personally hard to manage.

Participants spoke of their own support needs with some finding moving to teleHealth beneficial – if they had a known provider – and others reporting that as they had lost employment they couldn't afford the gap in fees of a mental health provider, despite being on a mental health plan. Providers who bulk-billed had lists longer than 6 months.

Some participants spoke of being suicidal. These participants had not been suicidal prior to the pandemic and expressed a sense of doom and hopelessness for the young people they support.

“ *I just, just became suicidal, it was, it's never happened to me before. But I really felt like I went through, it felt like a break and felt like, Oh, I think something's broken. I don't know if it was, I can't sort of say, Oh, that was definitely caring responsibilities. But I think it was the whole experience of COVID. And, you know, that sense of doom? And? And I mean, no, it definitely did have something to do with a sense of what, what is the future for these for these, for these young people? (Australian Capital Territory, Mother).* ”

Physical health challenges were also experienced with back surgery, cancer diagnoses and heart conditions having delayed treatment. Participants reported

the ongoing role of seeking help, monitoring behaviours, providing guidance and emotional support across the two years resulted in physical exhaustion, headaches, weight gain, and stress related disorders such as shingles.

Participants also spoke of many positive occurrences arising from changes associated with the pandemic. These included a changed pace and focus of life, hopefulness that positive change practices may be maintained after COVID, new work and education practices, and stronger and improved relationships.

Increased levels of care provision

The Factors that led to increased levels and amounts of caring experienced arising from or during COVID-19

- Loss or reduction of support services
- Escalation of symptoms in the supported people
- NDIS placed added strain on family, especially where hours or services were cut abruptly

Family carers explored and described factors that led to increased levels and amounts of care and support experienced arising from or during COVID-19. The main areas of concern included increased levels through the escalation of symptoms in the supported people, loss of support services, increased contact with supported people, spending more time in the support role and working from home, which made it difficult to create boundaries around work time.

Engaging with the NDIS placed added strain on family especially where hours or services were cut abruptly, not only leaving the family to step in and provide the extra hours of support but also the abandonment felt by consumers, which increased their mental distress.

“ Cancellation of NDIS services without notice which were needed for my daughter's safety - meant I had to juggle my own work requirements and urgent caring tasks. When the person you care for is at extreme risk, it is already 24/7, then to have cancellation without notice of carefully negotiated supports puts intolerable strain on you. I have had to reduce my working hours (and income) because of this (Victorian, Mother).

”

Alongside the closure and loss of services, those who maintained services found that appointments were stretched out to monthly when they had previously been weekly.

Family and friends who would usually provide some support or relief were also unavailable, leaving the primary family carer with increased hours of support, supervision and care. Lone carers were especially vulnerable during periods of lockdown, in trying to provide support and maintain the health and safety of the person they supported for 24 hours a day.

One family carer participant wrote in the chat of the Zoom meeting;

“ I am unable to talk atm, my 16yo daughter is close by, but the isolation has created suicidal ideology from her that I deal with every day, and I find it difficult to get her through every day and find services that will help (Victorian, Mother).

”

Complexity of care provision

The Increasing complexity of care provision including intersectionality, multiple tasks/ services, roles and navigation.

- Family and friends usually provide providing relief were unavailable
- primary family carers experienced increased hours of support, supervision and care.
- Lone carers were especially vulnerable

An increasing complexity of care provision was noted by the participants including intersectionality, the multiplication of tasks and service interactions, different roles and responsibilities, and navigation of the changes within the system. Complexity increased through the need for ongoing advocacy work and planning both arising through COVID-19 but also from gaps in services that had been present prior to COVID-19.

“ A lot of my role as a carer is emotional support, but a lot of it is advocacy. Making enquiries about services and getting knocked back time and time again is incredibly disheartening (Western Australia, Mother). ”

Of note was the difficulty gaining access to Emergency Departments. One participant was so desperate for assistance she stated,

“ I refused to leave ED with her until someone did something” (Western Australia, Mother). ”

Many participants reflected on needing to ‘behave badly’ to get support and in advocating for their family member.

For some family carers the advocacy work was further complicated by the context within which the person they supported was living. A number of supported persons had become unwell during COVID-19 and had subsequently received a custodial sentence and were residing in prison or a secure hospital. Gaining access to visit and provide support required writing to ministers and executive directors.

Similarly, rigidity around rules seemed inconsistent and at times not reflective of the current threat from COVID-19. For some private hospitals, regulations were applied across all states despite states not having current lockdowns. Restrictive practices meant consumers were left without support of family or friends for extended periods of time leading to further mental health challenges.

Many spoke of the increasing variety of caring tasks, changed living and work circumstances, and the confined spaces led to family tension. Supporting a person’s mental distress, whilst educating them about the changing rules often furthered tension within households and placed added stress on the carer in safeguarding vulnerable people.

Family carers also experienced the strain of working from home and therefore the complexity of negotiating their time between providing support and working. Others spoke of long hours working away from home but then returning to undertake their support role as the person hadn’t had support from services that had been cancelled.

“ ...the mental health, it really took a toll because I was doing my job at home. And I was already like overworked because I was doing service delivery and was looking to work 10 to 12 hours sometimes a day and then coming back home and supporting. So that was quite, quite a tricky one, it pushed me to actually go and work part time now just to recover from, from that experience (Queensland, Mother). ”

Participants spoke of the added complexity of providing care and support in different places and geographical regions. The stress of being cut off from children and losing contact when they were unwell and not answering the phone.

“ I have major concerns about the well-being of my grandson, his mum took him up to Queensland, he's five and just before lockdown. So basically, fortunately, the lockdowns weren't as bad but I, I've really tried to support from a distance, and he doesn't engage very well over zoom, ...I guess I've had to trust that he will be okay in the long run (Victoria, Grandmother).

”

Complexity also arose within families in negotiating the different caring relationships such as partners, siblings, and children, as well as including age related caring activities alongside people with physical and intellectual challenges. Some participants spoke of caring for grandchildren as their child was in prison.

Factors leading to beneficial experiences

The Factors that both helped and supported positive experiences of family

- NDIS providers being consistent, providing respite and meaningful activity for the supported person
- Government initiatives of financial assistance/COVID payments
- Listening to the family to understand their approaches

Factors that were beneficial to the experiences of family and carers were explored. These factors were grouped within systemic responses, beneficial community and service programmes, and individual processes.

Systemic responses noted as helpful to family carers included rolling over NDIS plans without needing to go through further assessments. Similarly, when NDIS providers were able to maintain consistency across service provision enabling respite and meaningful activity for the supported person.

“ we have six hours a week, and that's Tuesday and Thursday, three hours each, and it's wonderful. We both look forward to it. It's just it really, really works. It could be more, but very grateful for six hours, and it's consistent. It doesn't, it hasn't ever stopped (South Australia, Mother).

”

Other Government initiatives around financial assistance through COVID payments were appreciated but also highlighted few were able to receive carer payments. Flexibility around work and education practices were also of benefit.

Family carers spoke of the way services were provided, including the skills and manner of clinicians, within community and service programs impacted their experiences.

Listening to the family carer to understand their approaches to health and adopting a more holistic and inclusive framing led to better experiences for the family unit including the supported person. Some spoke of the value of a responsive general practitioner, who took the time to listen and understand.

“ my husband has faith, it's very important to him. It's what keeps him sane and whole. Everyone else has ignored that. But the recovery coach came in and went what lights you up, and they said, my faith lights me up (Western Australia, Spouse) ”

Carer networks and carer support workers in hospitals and community family peer support services were highly valued. Both for the information and service navigation they assisted with but also for the sense of connection, practical assistance and hopefulness that arises from speaking with someone who has shared experiences.

Similarly, independent carer support groups and the actions of carer peak bodies were highly noted as being valued and beneficial to family. The sense of support and understanding heard when talking to people who have experienced or are currently experiencing what you are was prime to family feeling able to carry on.

“ [X] support group was great, and I got a place in a respite weekend which was so useful in helping me relearn how to focus on myself too. Any time I felt like I was talking with someone who got what I was going through was so valuable. The number of times someone I was speaking to about my sister made the effort to ask me how I was doing, and if I had support, every single time it was like being thrown a lifeline (Western Australia, Sibling). ”

Those family carers who were able to access respite spoke of the difference it made to their lives, both in the reduction of social isolation and also in having time to attend to own needs.

“ There were some day respite that [X], provided over that period of time that I was personally very grateful for, because I ended up meeting some amazing carers who, I feel are now lifelong friends. And those opportunities that I was given, really made huge difference in my life, even though you know, they're not that regular, but at the time, I just really need that I needed the timeout, even if it was just for the day, I needed to be around other people that understood me, and my situation, as a carer for someone with severe mental health (Queensland, Mother). ”

Beneficial individual processes included activities which enabled a sense of connection – to people and nature – and a sense of purpose, both for the family carer and the supported person.

“ And now I do work for them for an online platform called the care hub. And so, they pay me six hours a week to moderate that and drive engagement and then other fluctuating bits. But it means that I have something I'm accountable to and that has purpose (Western Australia, Mother). ”

Communities were more noticeable with people acknowledging each other during periods of lockdown. More family carers sought their own therapeutic counselling and support, alongside activities such as meditation, mindfulness and exercise.

Enhanced strategies and skills

The strategies and skills developed or opportunities to develop and practice during COVID-19

- Doing some fun things with family/the supported person
- Needing to ensure finding time for some activities for self
- keeping a sense of hope, for self and the supported person

Participants explored both opportunities to develop and enhanced strategies and skills utilised during COVID-19 including accessing support for self, establishing self-care practices and developing support skills.

A number of family carers lamented losing their relational role and one family carer's strategy was to work to regain that.

“ Strategies I use is to create moments where I can be "mum" and do some fun things with my son, rather than doing all of the harder, caring 'stuff' (New South Wales, Mother). ”

Family carers recognised the importance of their own health in being able to maintain their role of support. A number spoke of actively formulating and discussing with the person they support a carer safety plan. Despite family recognising the importance of activities for self, this time was often gained through finding periods when others were occupied or asleep.

“ I have a self-care, like my carer safety plan. Self-care is in different levels of daily, smaller things, larger self-care activities to replenish my sanity & then intervention self-care when the really hard 'stuff' happens. I'm learning how to find my voice and have conversations with appropriate people to educate and advocate regarding mental health. I have a Carer safety plan that I have shared with my son, links in with his safety plan (New South Wales, Mother). ”

An overall strategy was keeping a sense of hope both for themselves and the people they support.

“ But the one thing that I did do that helped was I noticed the seasons. It sounds kind of Daggy. But it helped me, not to pass time. But just note that things were happening, and no state lasts forever. And so, I found that helpful (Victorian, Mother). ”

Innovations provided that were or could be responsive to need

The new services or ideas that were responsive to consumer/family need that made a difference

- Carer support services, in community and mental health services
- Program innovations that increased connection
- Technology, with teleHealth seen as beneficial by a number of carers

Participants spoke of new services or ideas that were responsive to consumer and family need and that made a difference. Innovations included in community and mental health services or programs, within carer support services, and technology.

Program innovations that utilised models of care that were inclusive of family and cultural considerations were seen as important in both supporting the consumer and the family unit. These models of care were responsive, demonstrated age specific supports such as day programmes, alternatives to going to hospital and true participation processes.

Family carers felt the inclusion of family and consumers in governance positions, or in co-designing services would lead to changes in practices that would better meet the needs of consumers and family. An example of this was psychoeducation programmes which were seen as important especially when co-designed with family and family lived experience workforce.

Participants saw carer support services as important to family carers 'not falling through the cracks. Family lived experience

workers were found to be especially helpful in both working alongside families and in providing connections. Particular benefits were with innovations that increased connection especially where families were struggling. A suggestion being a service that family carers could ask to check in on them.

“ I'm a single mum now. And when everyone's busy with their own areas, my biggest fear is emergencies or big things happening. And being left. Not having anyone to help with my two children, being forgotten, then you know. Falling off the edge. Because sometimes you're in a moment, you don't necessarily have the capacity time, ability to call for help or to seek assistance on where to go, because you're so busy in the trenches, having somewhere, being on some system, someone checks in, make sure you're still alive, you can get out. Somewhere it being known. My biggest fear is not having help or assistance (Australian Capital Territory, Mother).

”

Technology was seen as beneficial; however, allowances need to be made to help with access and also considerations around people who don't experience teleHealth as therapeutic.

One aspect of technology that participants suggested could be used to increase inclusion with families was in utilising technology to increase connection where restrictions meant family couldn't or weren't allowed to visit.

Implications for policy and practice

The Implications where mental health system or services could make changes that could influence experiences

- Need for alternative safe space, instead of hospital
- That teleHealth is not usable or appropriate for many consumers
- Recognition of work of informal carers and the value they bring to the health system

Family carers discussed implications where mental health system or services could make changes that would influence experiences. These included the approach of services to engagement and communication, funding of mental health services, recognition of work of informal carers and the value they bring to the health system, a system better able to understand and respond to complexity, and teleHealth.

Both prior to and during the pandemic, family carers and consumers struggled to find services to meet their needs within the public system, meaning many had to look at private services which were either too expensive or the waitlists were excessive. Further to this, family requested services be set up to reflect age specific needs, especially for adolescents, where many had disengaged from schools.

“ Changes for a brighter future would be additional face to face support in assisting with increasing social skills to be better able to effectively engage in education and society again. A critical change for me is to have an alternative safe space for my son to go to, instead of hospital, when experiencing mental health distress. My son is now very reluctant to go to the emergency department now because of our previous poor experiences (New South Wales, Mother). ”

Similarly, the expansion of services for alternative places to go other than hospital and emergency departments, such as a peer support services or community-based facilities. Family discussed much of the increase in their support role was providing social, practical and emotional support, which are better provided away from a clinical setting.

“ there was an assumption that a lot of people with mental health problems could use technology to stay connected. My brother has zero ability to use technology, or to use a phone very well. And I use technology a lot. But even when I set up a computer, in front of him, he couldn't use it, he couldn't understand the concept of speaking to somebody. (Australian Capital Territory, Sister) ”

Whilst teleHealth was seen as having many benefits, a number of difficulties were experienced in both accessing and the suitability of teleHealth as a method of service provision for all people. Many family carers identified that either the person did not want to engage online or by phone, or were unable to comprehend engagement in this way.

Rural and regional participants identified access to internet and telephone connections can be very poor or not possible.

In considering system change, family carers identified that governance needs to be shared with clinicians, bureaucrats, consumers, and family, on boards and committees to elevate voices and promote system change.

“ There's not a respect for, for your expertise... that's something that's going to keep people from wanting to be within a peer role. Certainly, makes me want to jump out of a peer role, because I feel sidelined within organisations and, and I think that stigma that is attached to having a carer label. It's difficult, it makes life difficult, because people view carers in a certain way, historically within the community. So, I think innovation around how we're seen is something that coming out of COVID, I think that we have amazing carers who've done incredibly well to stay alive, incredibly well to, to keep their family members alive (Western Australia, Family peer worker).

”

Others spoke of government departments requesting involvement of participants in co-design of services, however the process was limited and not inclusionary, leaving family and consumers excluded at critical points.

Family carers also identified the value of lived experience workers within the system and the need for their valued expertise to be recognised, and opportunities available for advancement within the system.

Impact of system failure/ challenges on family and carer

The Underlying and pre-existing service gaps or insufficiencies that COVID-19 further compounded.

- Service gaps deepened the level of distress
- Trying to access services for suicidal/ highly distressed family members
- Financial supports very difficult to access

Family carers explored underlying and pre-existing service gaps or insufficiencies that were further compounded by COVID-19.

Service gaps deepened or exacerbated the level of distress experienced by carers leading to feelings of being overwhelmed. Challenges within the system, added increased levels and complexity of support responsibilities to the family and carers, especially when assistance was sought and nobody responded.

Family spoke of

“ trying to connect with anybody, I've rung every single person, every single group possible. And they all say they'll get back to me because it's urgent. And we're talking about suicidal ideation... really desperate situations and involvement with the police. They've been, you know, set things on fire and, you know, been in a lot of trouble. And yet, nobody ever gets back to me (Victoria, Mother).

Systemic challenges included concerns around financial and housing support, alongside service issues. Many participants spoke of trying to access service support for their family members who were suicidal and extremely distressed. Some of these participants were trying to manage accessing support across state borders. People were unable to gain support, with participants stating that service providers said

“ we can't help you. Sorry, you know, we don't have the beds...it's always excuses. And, yeah, my child's life is not important in the scheme of things, which is very distressing (Victoria, Mother).

Participants expressed difficulties accessing financial support through Government services such as Services Australia;

“ Centrelink want you to jump through hoops? And, oddly enough, they just keep sending back messages that say, oh, we need more information. I keep supplying them with the information they need. They keep asking for more. It's almost like they don't believe me. You know, how unwell my son is, even with the doctor's letters with everything (Queensland, Mother).

Demand for support and care provision by family carers was seen to be greater than resources available for family and carers. Family spoke of the need to access support for themselves for the first time. Some found this difficult to find and noted that services set up to help them such as Carer Gateway had processes in place that made it difficult.

Family sought information and education to understand how to best provide support and keep everyone safe.

Distress was also noted by people who worked in family worker roles with the level of need exceeding the number and hours of peer worker roles available during the pandemic but also prior.

Regional difficulties in not being able to access family peer support or other services were noted. Participants also discussed the loss of beneficial gains both systemic (NDIS) and service provision that had occurred prior to COVID-19.

“ ...more programmes for carers in my situation, that we can come together and sort of learn more about a complex condition, how to manage their condition at home. Because not always will you have access to a support worker. Because sometimes the access is only through a psychiatrist, psychologist sessions, you know, 15 minutes then over Red Rover, and then you're having to deal with something it might have triggered, a response from a young person or person, and then you're left to clean up the mess when you're not going to see that person [psychiatrist/psychologist], you know, four weeks, two weeks, six weeks. (Queensland, Mother).

”

SURVEY – WHO WE HEARD FROM

The survey was opened on the 9th of May 2022 and closed on the 18th of June 2022. Up until the survey was closed, 190 people commenced the survey. Eleven people who commenced the survey did not identify as being mental health family carers and were provided with a list of support agencies and exited through the survey. Of the remaining eligible participants, 101 respondents completed the survey.

All states and territories were represented except the Northern Territory (Figure 8), with the majority of people identifying as living in Metropolitan areas (Figure 9).

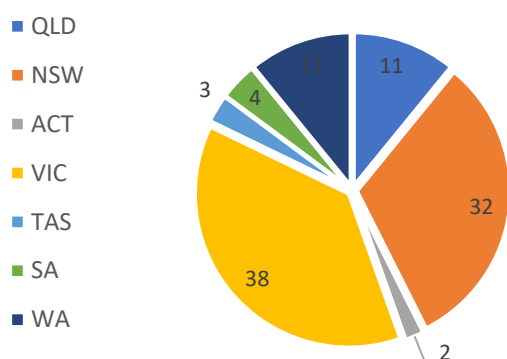


Figure 8 State of survey respondents

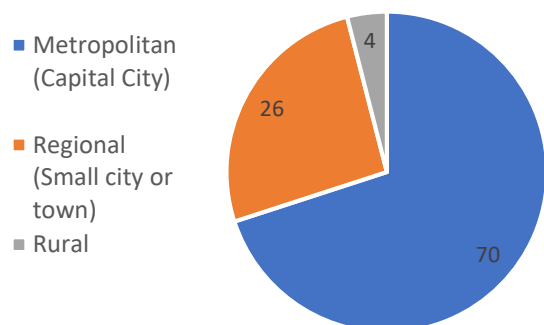


Figure 9 Survey respondent's geographical area

Ninety-seven of the respondents spoke English as their main language, with 2 people

speaking Hindi, 1 Filipino and 1 Greek. While the option was provided for people to identify if they needed assistance completing the survey, no-one reported this was the case.

The majority (88) of the respondents identified as female (Figure 10) and ages ranged from 18 to 80 years, with the average age being 54 years (Figure 11).

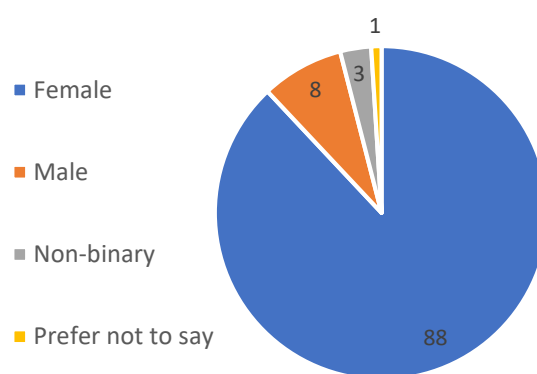


Figure 10 Survey respondent's gender

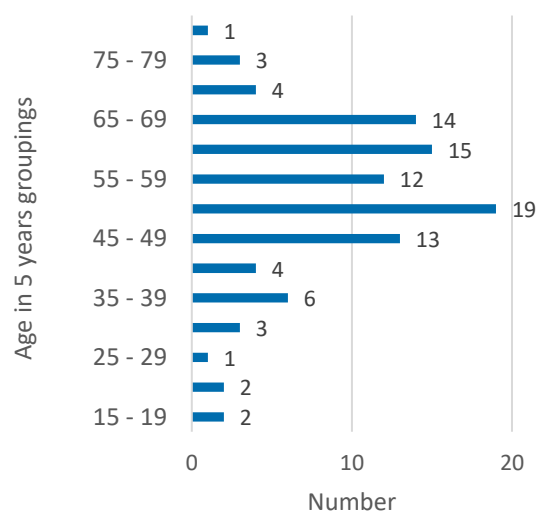


Figure 11 Survey respondents age in 5 years groupings

All respondents had completed senior level of schooling, with 30 people completing vocational training, 22 an undergraduate

degree and 43 had completed a post-graduate degree.

The majority of the respondents are long term providers of support and care and many of them identify also as a consumer (Figure 12).

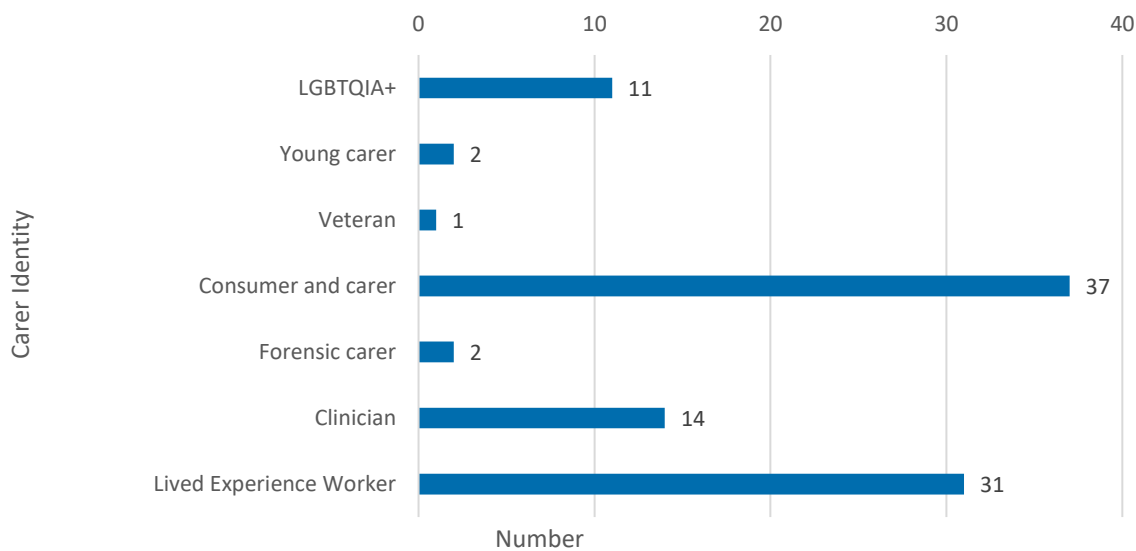


Figure 12 Identity of family carer

SURVEY – WHAT WE HEARD

Through the breadth and depth of the questions posed in the survey a fuller picture of the multiplicity of roles and experiences became clearer. At least half of family carers who responded were supporting more than one person and were typically supporting people with daily and high-level needs. Leading to an average of 40 hours a week spent providing support and an increased complexity of system navigation, advocacy and active knowledge of how to support and de-escalate situations and feelings of extreme distress in the person they support. People already experiencing mental health challenges prior to COVID-19 experienced

additional anxiety and depression brought about by fears around the virus, restrictions to movement, reduced and changed service availability and structure, and reduced access to hospitals. Many consumers returned to family homes throughout lockdowns, creating situations where multiple generations were forced to live in closer physical and emotional interdependence than they would choose. This emotional intensity and heightened levels of demands and responsibility became, for some carers, stress inducing to the point of suicidality.

DEMAND AND COMPLEXITY OF SUPPORT

Increasing levels of care

The level of demand on carers was increased, including

- More than half the carers supported 2 or more people
- Most carers live with the person they support
- Caring hours per week increased from 26.3 to 40.35 hours during COVID-19

More than half (51%) of the family carers identified they supported two or more people with mental health challenges (Table 1) and a majority of respondents reported being long term providers of support (Figure 13).

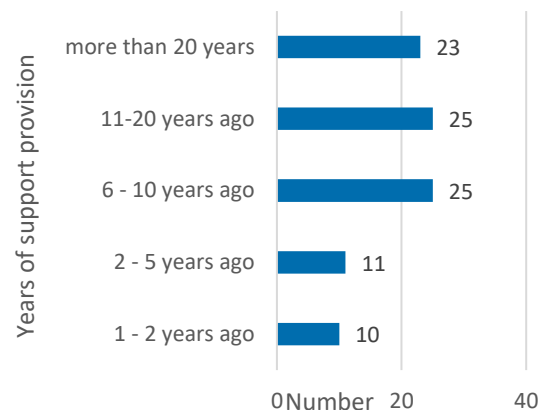


Figure 13 Years of support provision

Table 1 Relationship of supported people

Number and relationship of people with mental health challenges being supported	1		2	3	4+
Under 16 years	8		4	3	1
Young person (16 to 25 years)	31		6	2	3
Adult child (over 25 years)	31		7	2	3
Partner	33				
Parent	17				
Sibling	11		2		
Another relative	6		2		
Friend	6		8		3
Work colleague	5		1		
Ex-partner	2				

The majority of respondents are living with the person/s they support and were doing so prior to the pandemic (Figure 14).

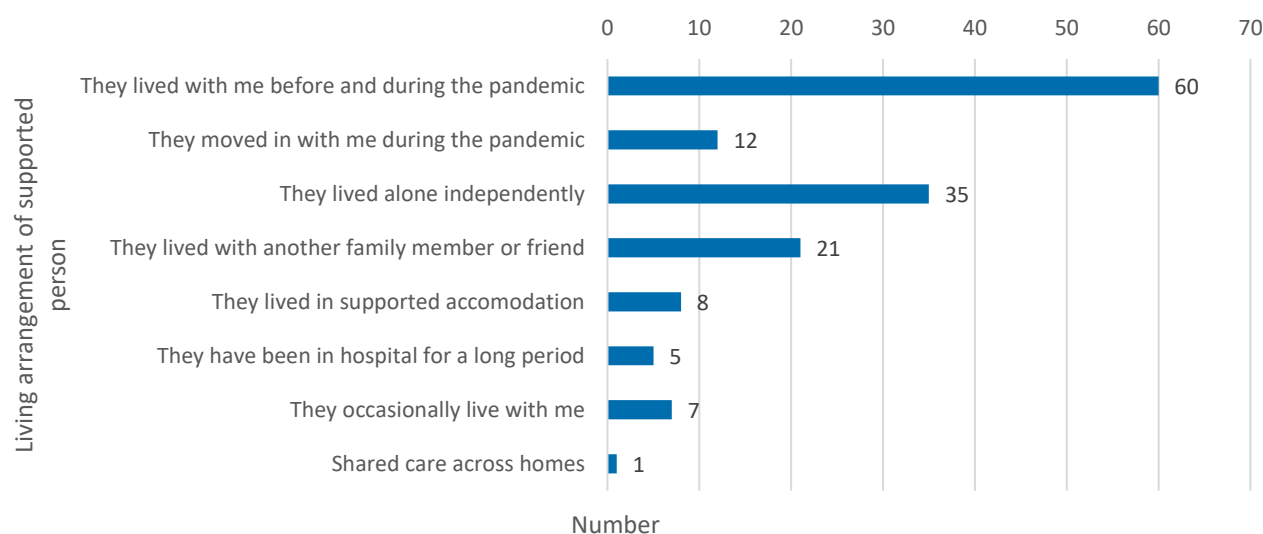


Figure 14 Living arrangement of supported person

There was a statistically significant ($p < .001$) increase in the number of hours a week that families typically spent on caring and support responsibilities during the pandemic compared to before the pandemic. Family carers reported spending on average 40.35 hours per week providing support during the pandemic compared to 26.30 hours per week prior to the pandemic.

“Increased vigilance and sense of responsibility for their [supported person] wellbeing. Increased stress and anxiety for self. Less time for my needs.” (ID 24)

The majority (57.4%) of respondents experienced a change in the way they provided support. The majority (73.3%) provided support in the family home, almost half (47.5%) also provided support in person outside the family home, 29.7% provided support online and 58.4% provided support via the telephone.

The change in the way care was provided and where care was provided led to increased demands on family carers in both the hours of caring but also in the emotional and practical aspects of providing support. Respondents noted increased hours of emotional support and checking in, with some family identifying that providing support by the telephone is more tiring than face to face.

“Challenging and tough to hear the depths of depression, self-harm and suicidal ideation. Challenging to have conflict with partner around how to best support our child. Intensity of family relationships during periods of isolation, with the mix of introverts and extroverts, and the different responses to online learning, working and isolation was tough. (ID 10)

The impact of this increased level of support provision meant increased demands on time, emotions, and finances. Families reflected on their experiences:

“ I have missed a lot of work and don’t have much sick leave or long service left. I need to care for her on my own without other support and this full-time responsibility is challenging. I feel so alone in this. (ID 106) ”

Further to this, family were impacted by the loss of services by consumers (Figure 15) meaning they had to increase the hours and activities of support provided, leaving many family carers feeling overwhelmed and socially isolated.

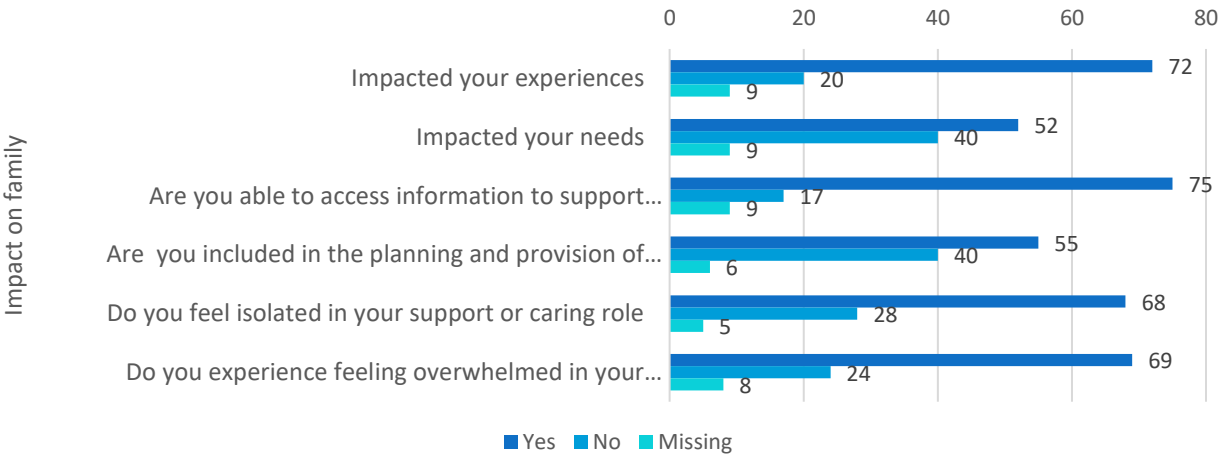


Figure 15 Impact of loss of consumer services

Complexity of support and care

Complex support and care experiences included

- Most supported people had multiple challenges
- Anxiety and depression were prevalent in care recipients
- Providing high emotional support necessitated reduced employment for most carers

The complexity of support provided by family carers was evident through the diversity of people supported across life stages, as well as the different relationships and symptoms experienced by the supported person.

This diversity increased the multiple forms of support such as emotional, financial, and practical, as well as the ways of providing support, which had been present before the pandemic but were also seen to increase in complexity. Changes in work and living arrangements and the state enforced restrictions enacted to combat the spread of the virus added to these complexities.

Family provided support to people with diverse identities (Figure 16), conditions and needs. Less than half of the respondents (43)

provided support to someone with only mental health challenges. The majority provided support across a range of and with co-occurring conditions (Figure 17).

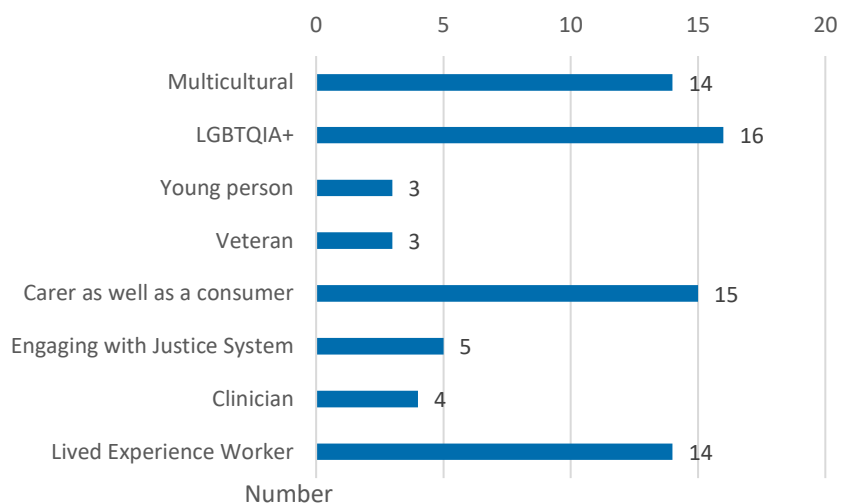


Figure 16 Identity of supported person

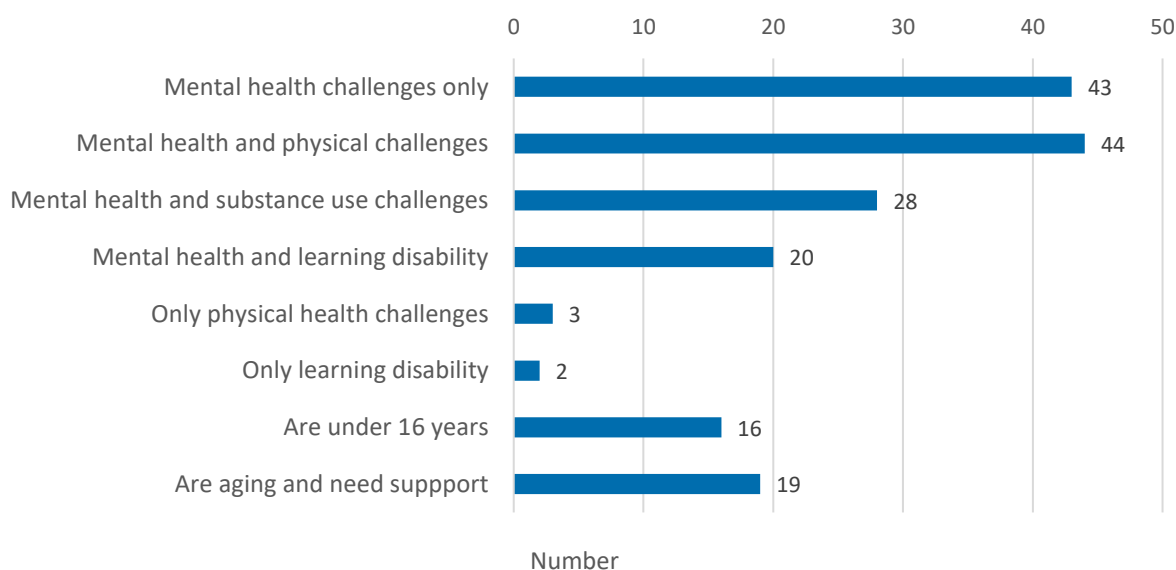


Figure 17 Conditions of supported persons

Family also provided support to people who experienced a diversity of mental health challenges (Figure 18). Of note 49 respondents were supporting either someone who was experiencing suicidal or self-harm behaviours, with 20 family carers

supporting people experiencing both self-harming and suicidal behaviours. The experiences of these family carers is often one of being alert and vigilant 24 hours a day 7 days a week.

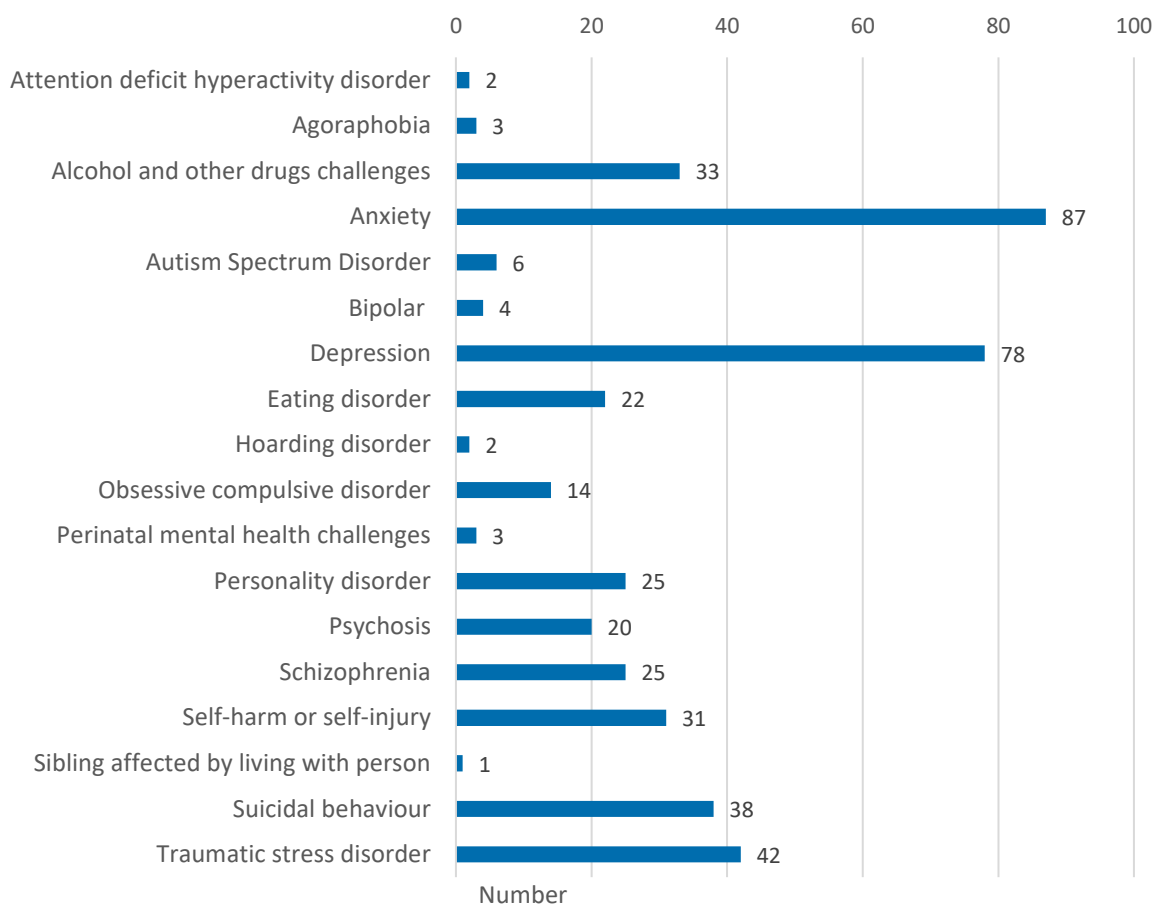


Figure 18 Mental health challenges of supported person

Family carers experienced complexities and stress around the impacts of COVID-19 on the support they provide (Table 2), including being worried about becoming sick and being able to provide support. The restrictions meant that there were fewer opportunities for family to receive support

from others, but also meant that practices such as working from home meant increased hours of contact with the supported person. Increased stress was also noted through managing other responsibilities in the lives of the family including work, housing and finances.

Table 2 Stress of COVID related impacts

Caregiving experiences compared to before the pandemic	More Stressful	The Same	I did not have this experience
I worry about getting sick and not being able to provide support and care	60.4%	22.8%	7.9%
Opportunities are limited to receive help from other care provision sources (such as other family members, community organizations, or home support services)	60.4%	14.9%	11.9%
Spending more time with the person I support	58.4%	22.8%	8.9%
Having other responsibilities, such as paid work, running a business, caring for children	57.4%	22.8%	15.8%
Limitations to being present with the person I support while they are in the hospital or during healthcare appointments	54.5%	16.8%	24.8%
Connecting with new supports	50.5%	19.8%	21.8%
My ability to visit the person I support is limited	48.5%	16.8%	23.8%
Getting information from the person I support's healthcare providers	40.6%	34.7%	18.8%
Accessing the medications and medical supplies that the person I support needs	36.6%	36.6%	20.8%

Restrictions arising from the pandemic and loss of services meant significant changes to the activities of support and also within the life of the family carer (Table 3). Most respondents reported increased provision of emotional support and the need to provide companionship and encouragement, in

helping the supported person to remain active and engaged with activities, as well as increased practical support provision in terms of shopping for groceries and other items and providing nutrition and financial assistance.

Table 3 Activities of support during COVID

Activities and the amount of support and care provided compared to before the pandemic	More support	The same	Less support	Support not needed
Providing emotional support	71.3%	17.8%	5.0%	3.0%
Providing companionship and spending time together	62.4%	18.8%	11.9%	4.0%
Encouraging or helping with being active	49.5%	30.7%	7.9%	8.9%
Supporting leisure activities	48.5%	25.7%	10.9%	10.9%
Monitoring physical status	47.5%	28.7%	4.0%	14.9%
Shopping for groceries and essential items	46.5%	31.7%	6.9%	11.9%
Coordinating services	45.5%	27.7%	3.0%	19.8%
Providing nutritional support	44.6%	31.7%	2.0%	18.8%
Supporting effective sleep practices	44.6%	26.7%	3.0%	21.8%
Providing financial support with your money	43.6%	26.7%	3.0%	23.8%
Scheduling healthcare appointments	39.6%	30.7%	5.0%	17.8%
Contacting providers of services	38.6%	35.6%	4.0%	18.8%
Assisting with activities of daily living (assistance with personal care routines, making meals etc.)	38.6%	28.7%	5.9%	21.8%
Managing suicidal thoughts and behaviours	37.6%	23.8%	3.0%	31.7%
Reminding about medications	32.7%	39.6%	3.0%	19.8%
Monitoring self-injury or self-harm	31.7%	19.8%	2.0%	42.6%
Assisting the person with managing their money	26.7%	33.7%	3.0%	33.7%
Monitoring harm with alcohol intake	24.8%	16.8%	5.0%	49.5%
Assisting with applying for NDIS package	21.8%	8.9%	2.0%	61.4%
Monitoring harm with drug or other substance use	18.8%	14.9%	4.0%	56.4%
Managing NDIS package	17.8%	13.9%	3.0%	58.4%

Many family carers experienced adverse impacts from providing support. One well evidenced is the impact on employment. The family carer respondents identified that prior to COVID-19, their responsibilities in providing support meant that 12.9% had to work less than 35 hours a week, 5.0% could not work, and 5.9% received a permanent Government benefit. Almost half of the respondents (41.6%) identified that their employment changed because of the COVID-19 pandemic.

Many commenced working from home, and reported the need to reduce hours of work to manage support responsibilities, whilst others increased work load to maintain the family income due to others losing work. Family carers identified that having to work from home reduced the opportunity for respite that work had previously provided.

“ Because of my caring role and health issues I have found it difficult to maintain a proper job and income. There is nothing out there that will help me to better my life under these circumstances. (ID 9) ”

Family carer respondents reported that 24.8% received carer allowance and 14.9% received carer payment. Reasons for not receiving financial Government assistance included family member not providing details or not wanting to support an application (concerns around stigma), lack of energy and time to apply, confusion over

eligibility, delayed time in considering application, fear of reducing status of supported person, partner receives the carer allowance, and not listed as carer once children turned 18.

Further to this family carers reported other economic impacts including through higher costs associated with travelling for treatment and support (37.6%), medication costs (47.5%), and fees for mental health services for the supported person (37.6%). Family carers also reported reducing spending in other areas to pay for support related expenses (44.5%) and borrowing money to pay for support related expenses (22.8%).

Increased understanding

Family also reported that spending increased time together and having to assist with system navigation, gave family increased insight into “the complexity of his mental health struggles” (ID 33).

LEVELS OF STRESS EXPERIENCED

A paired sample t-test explored the difference between levels of identified distress of family carers prior to the pandemic and within the past 2 weeks. There was a statistically significant ($p < .001$) increase in scores from prior to the pandemic (mean = 4.83; SD = 2.108) to (mean = 6.34; SD 2.442) in the past 2 weeks, with a medium effect size (Cohen’s $d = .66$).

Respondents were asked to rank the time during the COVID-19 pandemic when respondents experienced more stress, with most people (30.7%) ranking the beginning of the pandemic as most stressful (Table 4).

Table 4 Period of pandemic when most stressed

Period	Ranked most stressful (%)
January 2020 to June 2020 (Beginning pandemic)	30.7 %
July 2020 to December 2020	11.9 %
January 2021 to June 2021	9.9 %
July 2021 to December 2021	16.8 %
January 2022 to June 2022 (Now)	16.8 %

Factors that led to the ranking of that time period included:

(1) The beginning of the pandemic – the initial uncertainty and changing rules led to stresses of how to provide support within the restrictions especially if the person was living away from home, many noted increased symptoms at the beginning including suicidal behaviours, as well as the difficulty of supporting first episodes of psychological distress, respondents also identified the lack of respite available for people who were providing support in their own home;

(2) As the period of restrictions carried on respondents especially noted young people experiencing crises and supports weren't available or they were being placed on long waiting lists. This extended wait list time included when people were suicidal resulting in the family carer having no sleep through being with the person or checking on them, this period marked a rise of eating disorders in young people;

(3) towards the end of the pandemic – the loss of Government protections led to uncertainty including, people being evicted from their rental properties, loss of income support and not enough money to cover the basics, and the reduction in mandated health protective measures led to increased incidences of COVID-19 in the family and supported persons. The ongoing nature of the pandemic adversely impacted mental health challenges creating break downs in family units.

“ this has impacted my job, my relationships, my mental health, my ability to care for myself and my other children, my ability to contribute to the care of my elderly parents, my ability to contribute to society. Everything has been impacted negatively (ID 114). ”

Respondents were also asked to identify the level of stress arising from COVID-19 related stressors (Table 5).

Table 5 COVID-19 related stressors

Degrees of stress experienced by family (scale 1 not stressed to 6 extremely stressed)	Mean	SD
Concerns about the people you support becoming infected with COVID-19	4.51	1.40
Another member of your family or close network being infected with COVID-19	4.35	1.36
Concerns about becoming infected with COVID-19	4.28	1.34
Maintaining lockdown restrictions	4.20	1.25
A member of your family or close network dying from COVID-19	3.86	1.78
Accessing testing facilities	3.42	1.59
Accessing accurate information about COVID-19	3.28	1.39
Assisting the person you support to get vaccinated against COVID-19	3.24	1.64

Suicidality – suicide prevention service responses for family members

Suicidality in carers presented as

- More than 1 in 4 carers surveyed experienced suicidal thoughts
- This was in the context of excessive demand: work; isolation; feeling helpless and powerless to help the supported person; being in close contact with a loved one who was distressed, threatening or themselves suicidal
- For young carers isolation from friends and educators lowered energy, motivation and interest in living.

Nearly a third (26.7%) of family carer respondents identified they had thoughts of suicide during the pandemic. The Australian Institute of Health and Welfare (2022) identified that in 2020-21, 1 in 6 (16.7% or around 3.3 million) of Australians aged 16–85 had serious thoughts about taking their own life at some point in their lives.

When asked about the circumstances around these thoughts, family carers identified it was a way of escaping the difficulties of coping, supporting someone with suicidal behaviours, of being overwhelmed, especially around managing ongoing responsibilities for people's wellbeing.

“ More of an escape rather than wanting to actually be dead. It's all too hard sometimes. (ID 12)

”

The combination of the demands of work; isolation; feeling helpless and powerless to help the supported person; being in close contact with an unwell person who was threatening and shouting 'constantly'; housing instability; and relationship breakdowns left people feeling exhausted and unsure how to carry on.

“ Keeping financial concerns to a minimum, and keeping people safe (suicidal ideation and self-harm) when I couldn't physically be there with them (ID 46) ”

Many spoke of feeling dismissed and devalued; they expressed a lack of support and understanding from emergency services and health services and the impact of long-term advocacy to services for support.

“ My son almost lost his life 5 times, I didn't think I could cope any longer. But I did and I never had any intention of following through. (ID 9) ”

Young people who provide support spoke of isolation from friends and lower amounts of support from peers and academic professionals influenced their lacking energy, motivation and general feelings of interest in living.

Family carer's role in providing support for someone, in many cases being the only person left in supported person's life, stopped family carers from acting on their thoughts.

“ Worried constantly for my child - Increased isolation, self-harm, suicidality attempts, being able to get help (prior to CYMHS)- whilst juggling work, no sleep as either awake with child or checking on her. (ID 88) ”

The 27 family carers who had thoughts of suicide were asked if they were able to access help, 11 reported yes, 8 no and 11 said they didn't seek help.

Domestic Violence

Domestic violence was an issue presenting as

- More than 1 in 5 carers felt unsafe, afraid, controlled, or were physically harmed, by the person they support
- Supporting someone experiencing delusions and distress in close quarters during lockdowns was highly distressing for carers, as well as being distressing for the person themselves
- Only 1 in 3 carers needing support due to domestic violence received it

There was an increase in the experiences of domestic violence (Table 6) during the pandemic, however family carers (12.9%) also reported incidences of domestic violence before the pandemic.

Table 6 Experiences of domestic violence

During the pandemic,	Yes (n)	Yes (%)
have you felt unsafe or afraid, or felt controlled, so you are unable to do what you want to, or been physically harmed by a person you support?	23	22.8%
have you felt unsafe or afraid, or felt controlled, so you are unable to do what you want to, or been physically harmed by another person in your household?	20	19.8%
Before the pandemic	Yes (n)	Yes (%)
did you experience feeling unsafe or afraid, feeling controlled, so you were unable to do what you wanted to, or being physically harmed?	13	12.9%

Respondents reported both experiences of domestic violence for themselves and also for the people they supported. Incidences included feeling controlled by the person they supported through threats of suicide or from behaviours associated with mental health challenges such as autism spectrum disorder or during periods of delusions and distress.

“ Not physically. My partner (who I care for) was using their suicidality to keep me from saying and doing things that they didn't like (e.g. "Every time you tell me you can't see me, I want to OD on pills and alcohol") I felt controlled. (ID 46) ”

“ on several occasions I felt unsafe in the sense that I could not contain his slide into PTSD and acting out his distress (ID 109) ”

Family carers reported wanting health services workers to be aware that family carers may be in situations of domestic violence and that policies and training to be established to create this awareness and interventions to assist.

“ The hospital services had closed the mental health rehab, and the in patients was full, and my very ill son needed to be put in, but they didn't have room. This put me in danger, and was very stressful (ID 39) ”

“ More clinicians to be aware of how subtle family violence can look from the outside. I have had a clinician tell me that "name calling" and "being rude" is not grounds for family violence-look up the definition of emotional abuse. I would love to see a more holistic approach to family violence and have services more accessible to victim survivors (ID 58) ”

Of the family carers who experienced domestic violence, 21 identified they were able to take steps to manage their emotional, physical or sexual safety, 2 said they didn't, and 8 said they didn't seek support.

In reporting if they received support in relation to any harm or feelings of being unsafe, 10 said they received support, 9 said they didn't and 11 said they didn't seek support. Eleven family carers said they felt satisfied with the support they received.

The support family carers received included from long term friends, family, researching online, contacting the supported person's psychiatrist and using their own 'common sense'.

Some family carers went on to say that the support was not enough, that it didn't change anything but also that the little they received got them through.

Family unit distress

At times parents spoke of the trauma of a sense of outsider witnessing, where seeing a child, or family member in crisis with no access to mental health support was devastating to the whole family.

“ We were all broken and unable to support each other. Mental health and wellness has since become a priority, as such the costs associated (enough to hit our Medicare threshold by April this year) required both adults to take up full time work. (ID23) ”

“ Inpatient admissions were very distressing for my husband and for our family. He was isolated from his supports during admissions due to risk to the community being on hospital grounds...the nature of his admission [meant] he was away for 6 weeks with nil face to face contact with his children who are all under 11 years. This was their first experience of not being able to see their Dad when he was sick. This was a very difficult time for all of us and the transition back home was overwhelming for my husband. (ID 52) ”

Severe and persistent fatigue

Family spoke of being overwhelmed, 'burned out' and of severe and persistent fatigue, which led to them feeling they had lost the ability to support - *I am not able to provide as much support now. (ID 28).*

“ I have become an anxious person, always on the alert, trying to look out for him, keep him safe and ensuring his needs are met. Feel exhausted, but fail to get sleep, sometimes even guilty that my empathy is drying out. (ID 38) ”

Own health and social challenges

Many respondents identified their own health challenges and also feelings of isolation and being invisible. When asked

about their overall wellbeing (Table 7), the majority (59.4%) of respondents indicated that it was poor to fair.

Similarly, family carers reported their mental health (63.4%) as poor to fair, alongside poor physical health, sleep practices, energy

levels and exercise. Over half rated their ability to achieve the things that are important to them and their hopefulness for the future as poor to fair.

Table 7 Family carers personal health and social challenges

How would you rate your personal health and wellbeing?	Poor	Fair	Good	Very good	Excellent
Overall well-being	18.8%	40.6%	21.8%	15.8%	0.0%
Mental health	24.8%	38.6%	20.8%	11.9%	1.0%
Physical health	29.7%	25.7%	30.7%	10.9%	0.0%
Energy levels	40.6%	24.8%	26.7%	5.0%	0.0%
Exercise activities	40.6%	24.8%	22.8%	7.9%	1.0%
Balanced eating	24.8%	25.7%	31.7%	12.9%	1.0%
Sleep practices	37.6%	28.7%	22.8%	6.9%	1.0%
Management of substance use	5.0%	8.9%	18.8%	11.9%	42.6%
Quality of life	16.8%	36.6%	29.7%	10.9%	3.0%
Ability to achieve the things that are important to you	23.8%	33.7%	24.8%	11.9%	3.0%
Hopefulness for the future	25.7%	25.7%	23.8%	17.8%	4.0%

Many family carers expressed some of the personal health and social challenges as long-term concerns that existed prior to the COVID-19 pandemic.

“ I have felt isolated in my caring role for the larger part of thirty years until early this year when I started to participate in the [X] support program (ID 109)

”

“ A strong word. But the isolation of being blamed for my daughter's mental illness is deeply distressing. Fortunately, I have a supportive family and friends. (ID 71)

”

Support from people who have been in similar situations such as peer workers or peer support groups were identified as helpful in reducing the sense of isolation and being invisible.

“ Exacerbation of major depression, marked concern for all family members, feeling helpless and hopeless as I could not provide the level of care to family and friends that I previously supported, the weighty burden of isolation, my home was formally my sanctuary but work-from-home saw it transformed into a highly stressful prison, breakdown in workplace communication and accountability as the entire organisation moved to work from home which was hugely stressful and frustrating, worried about friends/family becoming unwell due to COVID, lack of access to health care services, inability to engage in social activities and travel (even local) became oppressive, poor sleep patterns, lack of motivation, increased alcohol use, weight gain and poor nutrition (ID 56) ”

“ *The stress of providing care during the pandemic has impacted my sleep. The person I care for also suffers from severe sleep issues and I am often awake into the early hours trying to assist. (ID 72)* ”

“ *More carer responsibilities means you let go of the physical care for self. Time poor. (ID 74)* ”

Many family carers sought support for their own needs through psychological services and counselling when available. Others would have liked to have accessed these services but were unable either through cost, lengthy wait times or no services available.

The general practitioner was the most utilised support service (54.5%), then online or telephone family support service (36.6%), private health services (28.7%), online counselling (21.8%), face to face counselling (15.8%), mental health community service (10.9%), and face to face family support service (9.9%). Family carers reported that they had to prioritise services for the person they support (28.7%) and couldn't afford services for themselves (23.8%).

Family carers also utilised support groups (28.7%), away from home respite (10.9%), and in-home respite (5.9%).

Exclusion from service settings and treatment decision making

Family carers – the people providing high levels of mental health care during COVID – were frequently

- Not able to access services for family members in need
- Not included in planning and decision-making about treatment they were then expected to monitor/enable
- Grateful for those occasions when specific workers included and supported them

Family within the focus groups and in the survey identified the need to be persistent to gain services, to receive information and be included in the planning and provision of treatment.

“ *My mother's psychiatrist is not open to involving carer input. It was like that before COVID and will likely remain so (ID 45)* ”

“ *As she was 17 when admitted to the MH hospital we weren't allowed to be told anything as per her request though she had mental health issues and had never been away for this long (ID 101)* ”

Being a nominee was identified as making a difference.

“ Only because I advocate for it. I have often been told families and partners are rarely involved, we don't need you or don't know what to do with you (ID 122) ”

However, family spoke highly of the positive impact a helpful service worker can be –

“ What helps is when a caring healthcare worker is supportive. (ID44) ”

And the benefits that can arise when services work collaboratively

“ Hospital and community mental health services were supportive in working collaboratively with my son, his father and myself (ID 44) ”

Navigation needs through peer navigation

Family carers identified feeling excluded from services and at times found it difficult to find information for themselves to meet their own needs or to fulfil their caring role for the person they support.

Many turned to access information from the internet, but also identified it took time, which they often didn't have available. Other sources of information included published reading material, friends, online applications, and supported family carer activities through hospital services. A respondent who provided support for an

aging relative alongside a person with mental health challenges noted

“ I was told I could get support as a carer for my father who is aging but not my partner as caring for someone with mental health is not acknowledged (ID 122) ”

Many respondents identified that peer workers or peer support groups were also helpful in understanding and learning how to navigate the system. Some services limit access to peer support to a specified period after discharge (often two weeks). A family carer felt like there may be many supports available but is just learning about them.

“ They have a lot on their plate and there are people who need more help than me. But as a Carer for chronic illness sufferer and ensuing emotional challenges, would love a mental health plan for Carers also from the beginning of the journey. I could have handled things better if I had that awareness (ID 38) ”

The impact of people returning to the family home or spending more time at home together because of the restrictions, made it

“ Extremely difficult and impacting on my own mental wellbeing as there was no respite time and emotions and behaviours were heightened (ID 75) ”

“ Managing the reactions of my family members, some struggled more than others. Becoming a kinship carer for an extended period, I would not seek this responsibility voluntarily. But neither would we want a young person to be homeless. (ID 57)

”

Respite

Respite was especially important, with carers noting the need as

- 3 in 4 carers were unable to join social activities
- Almost 60% experienced low family life satisfaction
- Respite was provided under previous funding models, so is experienced as a loss

Family carers (77.3%) also identified that they were unable to participate in social activities and 59.4% rated their family life in general as fair to poor. Respondents hoped a future system would provide respite that recognised both the need of the family carer and was also of value to the person they support.

It was noted the importance of respite for family carers to have time to think about and prioritise needs for the supported person and their own health needs.

“ Regular flexible respite options for myself as a carer based on my needs, that will also provide the right kind of care for those I care for so I can take breaks (ID 90)

”

Mobile centre response – disaster (impossible to get to help)

Family carers reported that as a result of the pandemic they were unable to receive practical (64.4%) or emotional (58.2%) supports from family and friends when they needed. Family suggested the need for services that could be mobile and responsive to their needs.

teleHealth

Whilst some respondents identified benefits of online and phone health services, including for themselves, such as reduced costs and time in attending, many identified that the lack of face to face engagement with service providers lead to the person they support disengaging from the service,

“ daughter hated online video therapy...attended less often as a result” (ID 113).

”

“ Being both a carer and consumer has given me a lot of stress and anxiety....needing face to face support and not being able to get it has been difficult. Online support is okay but is not the same. (ID 74)

”

“ The use of teleHealth was really hard for appointments for psychology and psychiatry when my young people refused to engage in that way. (ID 80)

Older carer fears/ if unwell

”

Whilst family carers across the majority of age groups identified that they were more stressed and worried about getting sick and not being able to provide support and care to their family member, it is apparent that for older family carers this is a concern they experienced prior to the pandemic (Figure 19).

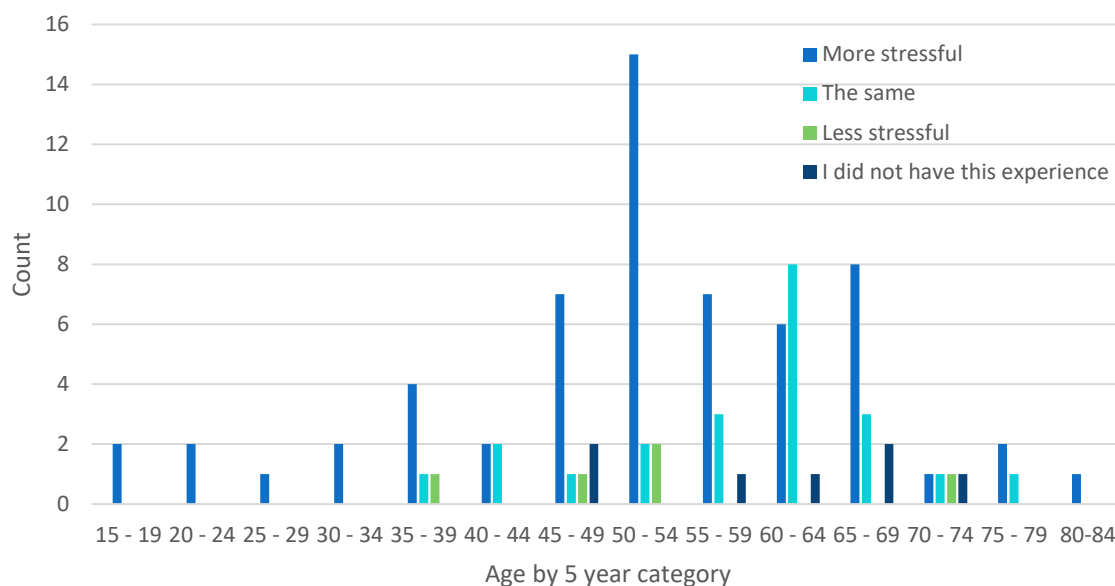


Figure 19 Worry about getting sick and not being able to provide support and care

Beneficial innovations for family carers

Family carers identified factors that assisted them or that they felt would assist them, including access to employee assistance programs to assist with workplace stressors, access to free legal or financial help, mental health disorder or challenge specific groups for support or psychoeducation, practical supports, and having information about what is available for families within the mental health system.

“ I actually felt less isolated than before the pandemic as I was able to access quite a lot of activities via Zoom on weekends and evenings that otherwise wouldn't exist. (I often can't do things during the day on weekdays as I work full time) (ID 93)

”

Others identified the gains experienced through the pandemic from activities occurring by Zoom.

PART 3 WHAT NEEDS TO HAPPEN

SITUATION INTERNATIONALLY AND PRIOR TO COVID-19

Through a survey of 9,000 unpaid carers across 12 countries, The Global Carer Well-Being Index study (Embracing Carers, 2021) found that the COVID-19 pandemic forced many people to – for the first time – take on caregiving roles and responsibilities (20% of informal carers self-identified as first-time carers as a result of the pandemic). Furthermore, findings indicate that the pandemic increased stress and demands on carers, with 2 in every 5 carers (39%) reporting increased caregiver workload (IACO, 2022). Without adequate support for carers and the role, the increased demands are being found to have far-reaching effects on various aspects of the carer's life during this challenging time.

These findings extend the seminal work that is the Global State of Care report (IACO, 2018a, 2018b), and the subsequent Global State of Care report (IACO, 2021). Of practical relevance to the current study are the 2021 Global State of Caring policies and practices across 18 countries that have prompted initiatives to address what have been named as the six universal carer priorities:

Recognition: Legislation and awareness campaigns

Financial support: Income support, pensions and benefits

Work and education: Carer-friendly workplaces and educational initiatives

Health and well-being: Health and social supports

Information and knowledge: Resources and education

Evidence-informed practices: Innovative policies and practices

“ While there has been well-deserved and vocal recognition and thanks for frontline health care workers and medical leaders, the substantial levels of care provided by carers has not been recognised in the same way. Caregiving is often seen as a personal and private matter in family life. As a result, the essential role carers play in minimizing impacts on the health care system can easily be overlooked.” (IACO, 2022, p. 5). ”

Our report has found that carer workload increased, from an already high 26 hours a week to 40 hours a week on average during the pandemic; an extra 14 hours a week. This tendency mirrors the experience in the United Kingdom, where 70% of carers are providing more care, with on average the carers providing 10 additional hours of care each week (Carers UK, 2020). This is higher than rates in the United States, where the average hours of care provided each week has increased by 7.5 hours per week, and 30% of carers have stated they are spending over 40 hours per week in the provision of care (Embracing Carers, 2020).

Our study found a comparable finding to that which was reported by Carers Australia (2020) earlier in the pandemic: that in Australia carers experienced an increased role since the person they care for lost access to services and respite care as a direct result of services being limited, less direct contact and/or people limiting contact with others.

There have not been sufficient health and social policies and programming, internationally, to support the needs and contributions of carers. Supports should meet carers' own physical and mental health needs and also facilitate opportunities for social connections and interests carers hold to pursue outside of their caring responsibilities (IACO, 2020, p. 16). The burden of isolation carers have faced through the pandemic is disquieting: in Canada, caregiver anxiety increased from 32% to 78%, and loneliness increased from 44% to 86% (Jasneet & Anderson, 2020); in Japan, mental burden and stress increased by 55% for carers (Japan, 2020); and in Israel, 40% of carers have reported feelings of depression and of hopelessness, with many carers also reporting they do not have access to counselling and support (Caregivers Israel, 2020).

SUMMARY OF WHAT WAS HEARD

Focus groups

To summarise, the focus groups found that during COVID-19 services reduced hours, closed or changed modes of practice that only suited some people. The experiences contributed to carers being overwhelmed, feeling distress and fear, and increased burden.

Survey

Through the survey further details emerged. Carers are frequently supporting more than one person and typically supporting people with daily and high-level needs. Caring increased during the pandemic to an average of 40 hours a week (up from 26 hours) spent providing support and increased complexity.

In people already experiencing mental health challenges prior to COVID-19, additional anxiety and depression was triggered by restrictions to movement, reduced and changed service availability and structure, and reduced access to hospitals.

Consumers returned to family homes throughout lockdowns, creating more complex and intense situations of physical and emotional interdependence than they would choose. This emotional intensity and heightened demands became, for some carers, stress-inducing to the point of mental ill health and suicidality for themselves, in addition to experiences of loved ones.

Diversity of voices

Efforts were made to reach culturally and linguistically diverse family carers through a planned focus group and 20 respondents to the survey identified as part of this community. Needs heightened within this group included the presence of suicidal thoughts and distress within members of the community experienced through racism, and separation from family overseas.

Through the focus groups we heard during COVID-19 services operated on reduced hours, closed completely or changed to modes of practice that did not suit people with mental health challenges and psychosocial distress. These experiences contributed to feelings of being overwhelmed, of distress and fear, and burden in family members.

For some family carers this was their first experience of this level of mental health distress and needing to access supports, for others these circumstances exacerbated pre-existing demands and difficulties accessing care and support for loved ones and in their own right.

Suggestions and solutions from family carers varied some of which was according to age, life stage, cultural identity, gender and multiplicity of caring responsibilities, and own health needs and challenges.

CONTEXT IN RELATION TO THE PRODUCTIVITY COMMISSION

The Australian Government *Productivity Commission Inquiry Report on Mental*

Health, Report no. 95 (Productivity Commission, 2020, chap 18) made a number of relevant points and recommendations with regards to the needs of carers and families and changes required as a result. The Inquiry (Productivity Commission, 2020, p.867) noted:

Support for carers and families matters because ...

- *Almost 1 million carers provided regular assistance to a partner, family member or friend with mental illness in 2018.*
- *This caregiving role provides great value to people with mental illness, carers and the broader community.*
- *Carers could also be of great assistance to service providers, if service providers were more willing to draw on the understanding and insights of carers.*
- *Caring also has costs — it affects some people's mental and physical health, social participation, career trajectory, educational attainment and financial security.*
- *Carers are not the only ones affected by a family member's mental illness — children who have a parent or sibling with mental illness may particularly need support.*

Explicitly (Productivity Commission, 2020, p.868) recommendations are:

RECOMMENDATION 18 — SUPPORT FOR FAMILIES AND CARERS

Governments assist families and carers by funding support services and income support payments. There is scope to improve access to these supports and to improve how families and carers are included by mental health services.

As a priority:

- *All mental health services should be required to consider family and carer needs, and their role in contributing to*

the recovery of individuals with mental illness. (Action 18.1)

– State and Territory Governments should be collecting and reporting on the Carer Experience Survey to encourage carer-inclusive practice.

– The Australian Government should amend the Medicare Benefits Schedule to provide rebates for family and carer consultations.

– State and Territory Governments should ensure the workforce capacity exists in each region to implement family- and carer-inclusive practices within their mental healthcare services.

Additional reforms that should be considered:

- *The recommended National Mental Health and Suicide Prevention Agreement (Action 23.3) should state that State and Territory Governments will be responsible for planning and funding carer support services related to the mental health caring role and family support services for families affected by mental illness. (Action 18.2)*
- *The Australian Government Department of Social Services should evaluate the outcomes achieved for mental health carers from its carer support program. (Action 18.2)*
- *The Australian Government should amend the eligibility criteria for the Carer Payment and Carer Allowance to reduce barriers to access for mental health carers. (Action 18.3)*

Beyond the moral imperative: the financial incentive to support carers

The benefits of the reforms recommended in chapter 18 of the Productivity Commission (2020, p.870) report are based on *the robust evidence-base about the effectiveness of family interventions and demonstrate the value of working with families and carers to support recovery. The Productivity*

Commission went a step further and modelled the impacts and effects of enhancing the support for families and carers on the mental health of carers themselves, care recipients, the children of parents with mental illness, and the cost-savings possible from reduced hospital admissions and from visits to the emergency department. The conclusion reached was that:

“ the annual economic benefits (from increased income and cost savings) from actions 18.1 and 18.2 totalled \$164–\$318 million, and exceeded the estimated annual costs of implementing these reforms (\$160–\$189 million). ”

The Productivity Commission report noted:

“ A primary caring role is typically equivalent to a full-time job. The average number of caring hours provided by all mental health carers was 11 hours per week, whereas it was 40 hours per week for primary mental health carers (Diminic et al. 2017, p. 138). Time spent caring significantly reduces the time available for the carer to participate and thrive in the community, through employment, education ”

and social interactions (Productivity Commission, 2020, p.876)

“ The Mental Health Respite: Carer Support program provided mental health carers with relief from caring through in-home or out-of-home respite or social and recreational activities, counselling, practical assistance, case management, education and information’ (Productivity Commission, 2020, p.904) ”

“ Cultural change that places greater emphasis on support for families and carers will take time but services that ignore the value of this are not operating in consumers’ long-term interests.’ (Productivity Commission, 2020, p.871) ”

The findings of the current report reiterate and extend findings and recommendations in the Productivity Commission report. Given this compatible information, there is a case to be made that the Australian Government immediately deliver on the 5 short-term recommendations and strengthen efforts to deliver on the 5 longer-term recommendations with an expedited timeline

RECOMMENDATIONS

The following recommendations have been developed through the voices and experiences of families which have been adversely impacted by the COVID-19 pandemic, but also speak of difficulties experienced through services not engaging with them or lack of systemic support in helping them to maintain a quality of life within their family and society/community. The 10 recommendations include 5 in the short term which could be actioned in 6 to 12 months. However, many of the recommendations echo and extend calls for change documented in previous policy documents including the *A National Framework for Recovery-oriented mental health services* (Department of Health and Ageing, 2013) and the more recent *Mental Health, Report no. 95* (Productivity Commission, 2020).

SHORT TERM

1. Australian governments to review practices in inpatient and other clinical settings to ensure family inclusion and partnership in supporting people with mental health challenges.
2. Australian governments to fund the creation of carer peer navigator roles – providing information and support – across inpatient and community services for families, carers and supporters.
3. Australian governments to prioritise the creation of carer on-call roles, accessible via local and regional mental health triage services, to respond to crises experienced by families.
4. The Australian Government to fund available and responsive mental health carer respite to ensure carer workload does not overwhelm family members so they are able to remain in paid work.
5. In order to respond to current and future major disasters (pandemics, fires, floods, and drought), Australian governments to create local and regional mobile centres for family assistance.

LONG TERM

1. The Australian Government to fund diverse modalities of consultations and therapeutic interventions to enable mental health consumer and carer choice, inclusive of but not defaulting to teleHealth.
2. The Australian Government, in recognising the risk inherent in providing long-term and acute mental health care on carers, to establish domestic violence services tailored and responsive to family members experiencing acute and/or cumulative risk and violence.
3. The Australian Government, in recognising the impact of providing long-term and acute mental health care on the psychosocial wellbeing of carers, to establish suicide prevention services responsive to family members experiencing acute and/or cumulative stress and distress.
4. The Australian Government to establish funded family-carer collaborative hubs to foster, mentor and disseminate family leadership in service redesign, evaluation and research.
5. The Australian Government to provide national guidance and co-ordination for innovation across all states in administration and guardianship as it relates to mental health carers concerned about the safety of loved ones in their absence or upon their death.

REFERENCES

- Australian Institute of Health and Welfare. (2022). *Australian prevalence estimates of suicidal behaviours*. Australian Government. <https://www.aihw.gov.au/suicide-self-harm-monitoring/data/deaths-by-suicide-in-australia/prevalence-estimates-of-suicidal-behaviours?fbclid=IwAR0vHoFE8-cL3T8rC6sUCvlyHs4hL1xEQv17UA1tbWnyjtmuwiVnAR-zrW8>
- Caregivers Israel. (2020). <https://caregivers.org.il/>
- Carers Australia. (2020). *COVID-19 income support and other government measures – Carers Australia policy response*. <https://www.carersaustralia.com.au/wp-content/uploads/2020/07/covid-19-policy-position-paper-march-2020.pdf>
- Carers UK. (2020). *Caring behind closed doors: Forgotten families in the coronavirus outbreak*. <https://www.carersuk.org/for-professionals/policy/policy-library/caring-behind-closeddoors-report>
- Department of Health and Ageing. (2013). *A national framework for recovery-oriented mental health services: Guide for practitioners and providers*. Canberra: Commonwealth of Australia
- Diminic, S., Hielscher, E., Harris, M. G., Lee, Y. Y., Kealton, J., & Whiteford, H. A. (2019). A profile of Australian mental health carers, their caring role and service needs: results from the 2012 Survey of Disability, Ageing and Carers. *Epidemiology and Psychiatric Sciences*, 28(6), 670-681. <https://doi.org/10.1017/s2045796018000446>
- Embracing Carers. (2020). *The US Carer Well-Being Index – Who cares for caregivers? Perspectives on COVID-19 pressures and lack of support*. https://www.embracingcarers.com/content/dam/web/healthcare/corporate/embracing-carers/home/document/United_States_Carer_Well-Being_Index_Report_FINAL_11.17.20.pdf
- Embracing Carers. (2021). *The Global Carer Well-Being Index. Who cares for carers? Perspectives on COVID-19 and lack of support*. https://www.embracingcarers.com/en_US/home/carersfacts/carerswellbeingindex.html
- Fusar-Poli, L., Surace, T., Meo, V., Patania, F., Avanzato, C., Pulvirenti, A., Aguglia, E., & Signorelli, M. S. (2021). Psychological well-being and family distress of Italian caregivers during the COVID-19 outbreak. *Journal of Community Psychology*. <https://doi.org/10.1002/jcop.22772>
- IACO. (2018a). *Global State of Care*. International Alliance of Carer Organizations.
- IACO. (2018b). *Strategic Plan 2018–2022*. International Alliance of Carer Organisations. <https://internationalcarers.org/wp-content/uploads/2019/11/IACOSTrategic-Plan-2018-2022.pdf>
- IACO. (2021). *Global State of Caring*. International Alliance of Carer Organisations.
- IACO. (2022). *The Impact of COVID-19 on Carers: An International Perspective*. International Alliance of Carer Organisations.
- Japan. (2020). *Request for emergency support measures for carers*. <https://drive.google.com/file/d/1e6RJyPKF0dFjGG9awGujmlanWo3iWfMs/view>
- Jasneet, J., & Anderson, S. (2020). *The impacts of COVID-19 pandemic on Alberta's family caregivers*. <https://www.caregiversalberta.ca/>
- Productivity Commission. (2020). *Mental Health, Report no. 95*. Canberra: Australian Government.

- Simblett, S. K., Wilson, E., Morris, D., Evans, J., Odoi, C., Mutepua, M., Dawe-Lane, E., Jilka, S., Pinfold, V., & Wykes, T. (2021). Keeping well in a COVID-19 crisis: a qualitative study formulating the perspectives of mental health service users and carers. *Journal of Mental Health*, 30(2), 138-147. <https://doi.org/10.1080/09638237.2021.1875424>
- Weinberg, M. K., & Cummins, R. A. (2015). The Distribution of Quality of Life in Australia. In (pp. 609-624). Springer Netherlands. https://doi.org/10.1007/978-94-017-9178-6_28

APPENDIX A TERMS OF REFERENCE



National Mental Health
Consumer & Carer Forum

December 2021

Terms of Reference

Carer Experience of Covid-19 Project Steering Group

Background

The National Pandemic Mental Health and Wellbeing Response Plan was released in 2020 to guide the Australian health sector response to the Covid-19 Pandemic. The Plan identified specific challenges to mental health and wellbeing associated with the Covid-19 pandemic and a range of measures to address the challenges. The Plan identified specific vulnerable populations more likely to have mental health and wellbeing challenges because of the Pandemic.

The National Mental Health Consumer and Carer Forum (NMHCCF) is undertaking this project, which is funded by the National Mental Health Commission, to focus on the impact of the Covid-19 Pandemic on levels of distress for the more than 240,000 people in Australia who are informal/unpaid mental health carers.

In defining mental health carers the NMHCCF includes all 'informal ' carers such as family members of any age, young carers, friends, kin, and broader family members.

The aim of this project is to develop an evidence base on the experiences and levels of mental health carer distress arising from the Covid-19 Pandemic, including identifying self-care strategies and unmet needs.

Purpose

The purpose of the Project Steering Group (PSG) is to provide advice and oversight to the Carer Experience of Covid-19 project.

The role of the PSG includes:

- promotion of the project to mental health carers through their networks
- participation in piloting survey tools
- review of project methodology and documentation
- review of project reports.

Term

The PSG has been established for the period of funding and will cease to operate on 30 June 2022.

Membership

The members of the PSG include four carers and one consumer member from the NMHCCF in addition to representatives from the following organisations:

- Mental Health Australia
- National Rural Health Alliance
- MIND Australia
- Mental Illness Fellowship of Australia
- National Mental Health Commission
- National PHN Mental Health Lived Experience Engagement Network (MHLEEN)
- Embrace Multicultural Mental Health
- Black Dog Institute - National Lived Experience Network of Aboriginal and Torres Strait Islander Peoples
- Mental Health Family and Friends Tasmania
- Arafmi, Queensland
- Helping Minds, WA
- Mental Health Carers NSW
- Mental Health Carers Australia

The NMHCCF's Strategic Projects Consultant will provide direction and oversight for the project. Proxies from organisations may attend meetings. The PSG will be Chaired by a carer member of the NMHCCF.

A list of the PSG members is provided at Attachment 1.

Meetings

- A decision quorum will be 50 percent of the PSG members
- Decisions will be made by majority vote
- The PSG will meet by teleconference or videoconference as required
- Work will also be required out of session via email
- Agenda, meeting papers and meeting minutes will be distributed to PSG members by the secretariat.

Project Steering Group members will:

- Commit to agreed timelines and complete tasks in alignment with the project plan
- Prepare for meetings
- Document relevant information to inform discussion
- Assist with editing drafts of documentation and project materials
- Actively participate in the PSG by providing feedback and comments in the emails and meetings

- Effectively and efficiently use Forum resources.
- Maintain confidentiality
- Declare any conflicts of interest

Role of Secretariat

To assist the Project Steering Group, the NMHCCF Secretariat will:

- Ensure, with the Chair, that the Terms of Reference are adhered to
- Organise meetings and take notes or minutes where appropriate
- Circulate documents to members in a timely manner (at least 5 working days prior to a meeting)
- Coordinate administrative processes as required
- Facilitate the payment of sitting fees for members' participation in meetings (as appropriate)
- Be the liaison person with any consultants
- Maintain oversight of project budget.

Attachment 1

Project Steering Group members

Name	Organisation
Eileen McDonald	National Mental Health Consumer and Carer Forum (NMHCCF)
Hayley Solich	NMHCCF
Kerry Hawkins	NMHCCF
Sharon Lawn	NMHCCF
Carli Sheers	NMHCCF
Nevena Simic	Embrace Multicultural Mental Health
Rachel Earls	National Mental Health Commission
Emma Coughlan	Mental Health Australia
Gabrielle O'Kane	National Rural Health Alliance
Tony Stevenson	Mental Illness Fellowship of Australia
Lynda Watts	National PHN Mental Health Lived Experience Engagement Network (MHLEEN)
Nicola Ballenden	MIND Australia
Vicki McKenna	National Lived Experience Network of Aboriginal and Torres Strait Islander Peoples, Black Dog Institute
Maxine Griffiths	Mental Health Family and Friends Tasmania
Alex Tyson	Arafmi Qld
Danielle Moore	Helping Minds, WA
Jonathan Harms	Mental Health Carers NSW
Katrina Armstrong	Mental Health Carers Australia

APPENDIX B FOCUS GROUP PROTOCOL

Focus Group Protocol –Family Carer experiences during COVID-19 in Australia

Focus Group and Interview Introduction Text and Semi-structured Questions

Thank you for agreeing to participate in this focus group to understand the experiences of family, carers friends and supporters of people with mental health challenges during COVID-19. This study is auspiced by the National Mental Health Consumer and Carer Forum and we thank them for their advocacy. We appreciate your time and hope that through understanding your experiences and those of others across Australia, we will be able to produce a report for the National Mental Health Commission to allow for future planning and awareness of the impact of pandemics on family, carers friends and supporters of people with mental health challenges. We expect the focus group to take up to 1 and a half hours.

With the invitation to this focus group, you should have received an explanatory statement explaining the purpose of the study and what will happen with the received information and the findings. The focus group will be recorded to allow us to capture your thoughts and notes may be taken whilst you are talking. The audio recording and our notes will be saved in a secure site at Monash University. Any information we receive will be deidentified and a copy of our findings can be made available to you.

Participation in the group is voluntary and you can leave at any time. As we will be discussing your experiences there may be times you feel upset or uncomfortable. Please take time for yourself if needed and you can ask one of the facilitators if you would like some assistance. We can also help you to contact counselling services or your state family peak body if required. Are there any questions you would like to ask before we commence? Can I confirm you have received the explanatory statement about the study? Your participation in the focus group indicates your consent.

Concept	Question
Demographics	Questionnaire handout or quick online survey • State • Postcode • Gender • Age • Identity
Support/ care provision experience	What has been your experience as a family carer supporting someone with mental health challenges during the COVID-19 pandemic? Prompt questions: • What impacts have these experiences had on your mental and physical health?
Practical challenges	What has been your greatest challenge or concern during the pandemic? Prompt questions: • How has COVID-19 impacted the way you provide support? • How has the family/ household structure changed as a result of COVID-19? • What changes have occurred that have influenced you financially?

Positive Impacts	What has been your greatest joy or positive experience during the pandemic?
Coping strategies	What disruptions have there been to routines or family activities? What strategies have you used to cope during the pandemic?
Service provision	What have your experiences of service provision been during the pandemic? Prompt questions: • What went well? • What helped? • What were difficulties or challenges? • Where did services fail?
Resources	What access have you had to resources during the pandemic? Prompt questions: • What access have you had to financial assistance? • What have your experiences of social support been during the pandemic? • What access have you had to information? • Have you any needs that have been unmet?
Innovations	Could you describe any new services or changes to services since the pandemic that have impacted your personal experiences or your experience of providing support?
Future	What changes would help with you envisioning a bright future with the person you support?
Further comments	Have you any further comments about your experiences

APPENDIX C SAFE SHARING

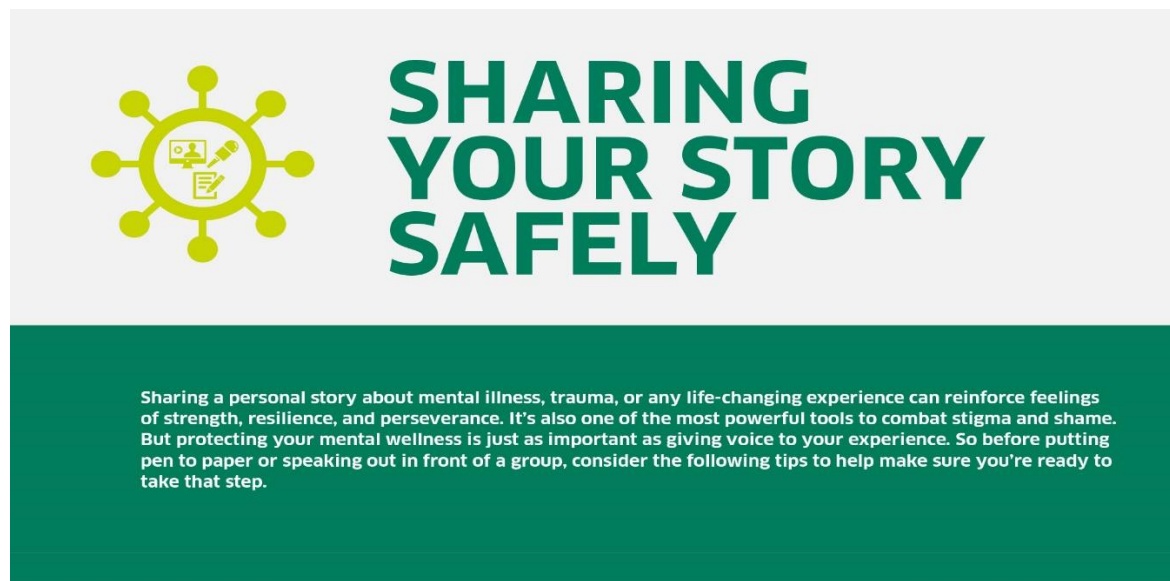


Figure 20 Sharing your story safely
<https://mentalhealthcommission.ca/resource/sharing-your-story-safely/>

Sharing a personal story about mental illness, trauma, or any life-changing experience can reinforce feelings of strength, resilience, and perseverance. It's also one of the most powerful tools to combat stigma and shame. But protecting your mental wellness is just as important as giving voice to your experience. So before putting pen to paper or speaking out in front of a group, consider the following tips to help make sure you're ready to take that step.

- 1. Take your time**
There's no rush, and no "right time" to tell your story. Consider checking in with a mental health professional, peer supporter, or trusted friend to see if now is a good time for you to speak out. If you decide it isn't, that's OK! Supporting mental health is important, but lending your voice shouldn't set you back.
- 2. Consider the implications for others**
If your story includes disclosing past traumas or divulging information involving loved ones, be aware that others may have different perspectives or different feelings about privacy. While your story is yours to tell, it's important to consider how your disclosure could affect those close to you. Remember that you can only control the delivery, not the response.
- 3. Choose the right outlet and scale**
Going public can be as small as a 280-character tweet or as big as an op-ed in a national paper. Whether you prefer the intimacy of a small group of friends or the anonymity of a room full of strangers, you control how and where you share. It's not the scale of the disclosure that's important, it's the freedom and empowerment you derive from it.
- 4. Be prepared to listen**
Disclosure can be contagious — which is partly what makes it so effective in combating stigma. Sharing your story, especially on a wider scale, may lead to confessions from friends and strangers. When someone hears or reads an honest account of a story that's

similar to their own, it can be the nudge they were waiting for to share their experience. If you're open to sharing, also be prepared to listen.

5. **Consider consulting subject matter experts**

If your story involves a suicide attempt, sexual assault, or other details that may be triggering to those around you, consider consulting with subject matter experts. They may be able to help you tailor your disclosure to reduce harm to vulnerable readers or listeners. No matter what you're sharing, try to use language that reinforces a message of hope.

6. **Mention specific mental health resources**

When sharing your experience, point to specific mental health resources if you can. Someone hearing your message may need additional support. If a certain tool, website, or organization has helped you on your journey, let people know where they can find them. The safe conversations resources in the Mental Health Commission of Canada's (MHCC's) toolkits for people who have been impacted by a suicide attempt and people who have been impacted by a suicide loss can equally be applied to mental health and illness more broadly. Consider using them and sharing with family or friends. For practical tips and resources on a variety of mental health topics, visit the MHCC resource hub.

APPENDIX D ETHICS APPROVAL LETTER

Monash University Human Research Ethics Committee

Approval Certificate

This is to certify that the project below was considered by the Monash University Human Research Ethics Committee. The Committee was satisfied that the proposal meets the requirements of the *National Statement on Ethical Conduct in Human Research* and has granted approval.

Project ID: 31516

Project Title: Australian family experiences supporting people with mental health challenges
Chief Investigator: Assoc Professor Melissa Petrakis

Approval Date: 04/03/2022

Expiry Date: 04/03/2027

Terms of approval - failure to comply with the terms below is in breach of your approval and the Australian Code for the Responsible Conduct of Research.

1. The Chief Investigator is responsible for ensuring that permission letters are obtained, if relevant, before any data collection can occur at the specified organisation.
2. Approval is only valid whilst you hold a position at Monash University.
3. It is responsibility of the Chief Investigator to ensure that all investigators are aware of the terms of approval and to ensure the project is conducted as approved by MUHREC.
4. You should notify MUHREC immediately of any serious or unexpected adverse effects on participants or unforeseen events affecting the ethical acceptability of the project.
5. The Explanatory Statement must be on Monash letterhead and the Monash University complaints clause must include your project number.
6. Amendments to approved projects including changes to personnel must not commence without written approval from MUHREC.
7. Annual Report - continued approval of this project is dependent on the submission of an Annual Report.
8. Final Report - should be provided at the conclusion of the project. MUHREC should be notified if the project is discontinued before the expected completion date.
9. Monitoring - project may be subject to an audit or any other form of monitoring by MUHREC at any time.
10. Retention and storage of data - The Chief Investigator is responsible for the storage and retention of the original data pertaining to the project for a minimum period of five years.

Kind Regards,

Professor Nip Thomson

Chair, MUHREC

CC: Ms Caroline Walters, Dr Melinda Goodyear, Dr Marcelo Maghidman

List of approved documents:

Document Type	File Name	Date	Version
Supporting Documentation	MH_Family Experiences Advertisement-Human-Ethics	20/02/2022	1
Supporting Documentation	MH_Family Experiences_Explanatory-Statement-Human-Ethics-short front of surveys	for 20/02/2022	1
Focus Group questions	MH_Family Carer Experiences_Focus Group Protocol	21/02/2022	1
Explanatory Statement	ID_31516_MH_Family Experiences_ explanatory-statement	21/02/2022	1
Consent Form	NMHFCC consent-form	01/03/2022	1
Questionnaires / Surveys	Survey for Ethics_MP q answers 21 Feb	01/03/2022	2
Supporting Documentation	MH_Family Carer Experiences_Focus Group Protocol_v2	03/03/2022	2

Monash University
Wellington Road
Clayton, Victoria 3800
Australia

T: +61 3 9903 4497
E: Melissa.petrakis@monash.edu

monash.edu.au