

## Submissions and evidence to the COVID-19 Response Inquiry – Mental Health Family Carers

I am a research and teaching associate and a PhD Candidate at the Department of Social Work, Monash University, and a member of the Social Work Innovation, Transformation and Collaboration in Health (SWITCH) Research Group located within the Faculty of Medicine, Nursing and Health Sciences, Monash University. My research practice and teaching are informed by my experiences as a mental health family carer and also through my role as a Senior Family Carer Researcher at Tandem the peak body for family carers in Mental Health in Victoria. Through research and advocacy, I hear and elevate the experiences of family and carers of people with mental health challenges.

As a member of SWITCH, I co-led research to understand the experiences of Mental Health Family Carers during COVID-19 in Australia. We worked alongside the National Mental Health Consumer and Carer Forum and engaged with and heard from Mental Health Family Carers from across Australia.

### Summary of SWITCH Research Group evidence

Internationally, people experiencing mental health challenges and psychosocial distress faced service disruptions, increased uncertainties and isolation, during the COVID-19 pandemic (Walters and Petrakis, 2022). Mental health family carers in turn experienced high levels of demand to step into the gaps in service responses within a context of fear and uncertainty. 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. A National Australian Study into the experiences of Mental Health Family Carers During COVID-19 in Australia (Petrakis and Walters, 2022), reinforced the international literature identifying that these carers provided higher levels of emotional and life-skills support, support and supervision with navigating health treatments, and were less likely to be identified as carers and receive Government support.

The data identified family experienced high levels of distress and concern about the loss of services and support, family members becoming infected during hospitalisations, accessing services including family members being able to visit highly distressed patients in psychiatric wards, inappropriate and early discharges, care provision if family carers became unwell and the need for targeted responses and quality for online services.

***Key health response measures (for example across COVID-19 vaccinations and treatments, key medical supplies such as personal protective equipment, quarantine facilities, and public health messaging).***

Government enforced restrictions of movement, travel limitations and physical distancing disrupted the provision of health services and limited access to health care facilities, resulting in the onus of care provision being placed, at times, solely on the family and supporters of people with mental health challenges. Rigid adherence to inconsistent and changeable health directions resulted in high levels of family carer distress and powerlessness over the prolonged period of the pandemic. Family Carers expressed being placed in impossible situations in supporting people who were left without services and who didn't live with them, including supporting people in other states. Family carers identified they risked being fined for movements contrary to Government enforced restrictions to

provide support to their highly unwell family members and not being able to find supports across state borders, resulting in family members becoming homeless or suiciding.

*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 yet, nobody ever gets back to me (Mother providing care across states).*

Public health messaging must consider people who are in active (non-paid) caring roles, identify strategies how these roles and the people who provide them can be supported, and provide access to protective equipment when these family members are essentially stepping into providing the care and treatment that clinical services were unable to provide.

### **Mechanism for future responses**

Australian governments to

- review practices in Mental Health inpatient and other clinical settings to ensure family support, inclusion and partnership in caring for people with mental health challenges,
- fund the creation of carer peer navigator roles – providing information and support – across Mental health inpatient and community services for families, carers and supporters,
- 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.

### ***Financial support for individuals (including income support payments).***

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.

*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.*

Time spent caring significantly reduces the time available for the family carer to participate and thrive in the community, through employment, education, and social interactions (Productivity Commission, 2020, p.876). Increased hours of care were reported with the average during the pandemic being 40.35 hours of care per week, compared to 26.3 hours prior to the pandemic. Employment was disrupted through the increased hours of support meaning decreased hours available for employment, or interruptions to working days. Family carers reported other economic impacts including through higher costs associated with travelling for treatment and support, medication costs, and fees for mental health services for the supported person, largely due to the loss of publicly funded support or extreme lack of providers in regional areas. Family carers also reported reducing spending in other areas to pay for support related expenses and borrowing money to pay for support related expenses.

Only a quarter of the family carer respondents reported receiving family carer allowance and 15% received a carer payment. Reasons for Mental Health family carers not receiving Government assistance include the unwell 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 unwell family member, partner receives the carer allowance, and family carer not listed as carer once children turn 18.

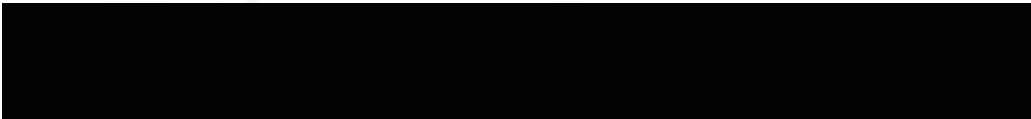
### **Mechanism for future responses**

Australian governments to

- Enable Mental Health Family Carers to seek assistance without the consent or need for information from the unwell family member.

***Mechanisms to better target future responses to the needs of particular populations (including across genders, age groups, socio-economic status, geographic location, people with disability, First Nations peoples and communities and people from culturally and linguistically diverse communities).***

The COVID-19 pandemic highlighted prior areas of Mental Health systemic support that had been missing and also the loss of services that had been of benefit to the mental health consumers and family carers and supporters. Mental health family carers are a vulnerable group, especially during periods of disasters, including pandemics. 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 –



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 mental health family carers to maintain a quality of life within their family and society/community.

### **Mechanism for future responses**

Australian governments to

- recognise the unpaid work and its impact on mental health family carers when services are inadequate or unable to respond to the needs of mental health consumers,
- create local and regional mobile centres for family assistance, to respond to current and future major disasters (pandemics, fires, floods, and drought),
- establish funded family-carer collaborative hubs to foster, mentor and disseminate family leadership in service responsiveness, redesign, evaluation, research and future planning.

### **References**

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 <https://nmhccf.org.au/component/edocman/mental-health-family-carer-experiences-of-covid-19-in-australia-final-report/download?Itemid=0>

Productivity Commission. (2020). Mental Health, Report no. 95. Canberra: Australian Government.

Walters, C. and Petrakis, M., (2022) Mental Health Family Carer Experiences during COVID-19: A Rapid Scoping Review of the International Literature, *The British Journal of Social Work*, Volume 53, Issue 3, Pages 1483–1505, <https://doi.org/10.1093/bjsw/bcac242>

Caroline Walters RN MSW (PhD Candidate)



[SWITCH](#) Research Group, Monash University

Department of Social Work, Monash University, Caulfield Campus