

CarersACT

MENTAL HEALTH
carers
voice



2023-2024 ACT BUDGET SUBMISSION

April 2023

Mental Health Carers Voice

The Peak Body for Mental Health Carers in the ACT

About Mental Health Carers Voice

Mental Health Carers Voice (MHCV) is the Peak Body for Mental Health Carers in the ACT and sits under the auspice of Carers ACT. MHCV actively engages with mental health carers to have their voice heard and create positive change in the sector through systemic advocacy. The MHCV Advocacy and Policy Advisory Group (APAG) provides a guiding voice for our Peak Body work. APAG is made up of mental health carers and provides MHCV with significant input, regularly consulting to understand current problems and major concerns within the community.

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Executive Summary

According to *the National Study of Mental Health and Wellbeing* released in 2022, one in five Australians experience mental illness each year.¹ In this context, it has been estimated that 15% of Australians provide care for people living with mental illness.² It is likely therefore that given Canberra's current population,³ over 75,000 Canberrans provide care for someone experiencing mental ill health, or have experienced mental ill health themselves. The *2021 Carer Wellbeing Survey* found that carers in the ACT were almost twice as likely to report low levels of personal wellbeing as the general population.⁴ Additionally, carers in the ACT were found to have a higher-than-average likelihood of reporting a fair or poor general health rating (53.5%) and experience poor financial wellbeing, with 36% of ACT's carers also often or always experiencing loneliness.⁵ For these reasons, the *ACT Wellbeing Framework* recognises carers as a vulnerable group that should be supported across all domains and recognised for their contributions to the community.

Foundationally, Mental Health Carers Voice (MHCV) asks that the budget consider the continued delivery of policy, programs and services which support the principles of the *Carers Recognition Act 2021* (ACT).⁶ Upholding this legislation in budgetary commitments will ensure recognition, engagement, and support for carers (including mental health carers) in the places they live, work, and engage in the community and services. Likewise, the *ACT Carers Strategy 2018-2028* ('*Carers Strategy*') also delivers a framework to recognise carers and the role they play in the community and sets out the actions to achieving a Canberra that "cares for carers".⁷ MHCV appreciates that funding for the *Carers Strategy* has been provided and recognises that the Government has fulfilled the majority of commitments to carers under *the Parliamentary and Governing Agreement for the 10th Legislative Assembly*.

MHCV is submitting two proposals to the ACT Government's 2023-24 budget. The first proposal is for the establishment of a dual diagnosis ward in the upcoming Northside Hospital, which will provide comprehensive and integrated mental health, alcohol, and drug services to address the gaps in support for people with dual diagnosis. The second proposal is for ongoing funding for mental health respite to address the significant gap in funding for respite to mental health carers, who often experience burnout, relationship breakdown, and poor health outcomes due to a lack of rest and support. We ask that the Government actively consider the need for a range of respite services, including day program care, institutional respite, and in-home respite, as well as community-based rehabilitation programs for care recipients and capacity building support groups for carers, all of which will have an immediate impact on the wellbeing of those

¹ "National Study of Mental Health and Wellbeing," Australian Bureau of Statistics, publication July 2022 (accessed March 2023), [National Study of Mental Health and Wellbeing, 2020-21 | Australian Bureau of Statistics \(abs.gov.au\)](https://www.abs.gov.au/statistics/people/population/national-state-and-territory-population/latest-release#states-and-territories).

² Jane Pirkis, Philip Burgess, Judy Hardy, Meredith Harris, Tim Slade, and Amy Johnston, "Who cares? A profile of people who care for relatives with a mental disorder," *Australian and New Zealand Journal of Psychiatry* 44, no. 1 (2010), 929, [Who cares? A profile of people who care for relatives with a mental disorder - PubMed \(nih.gov\)](https://pubmed.ncbi.nlm.nih.gov/19888888/).

³ National, State and Territory Population," Australian Bureau of Statistics, publication March 2023 (accessed April 2023), <https://www.abs.gov.au/statistics/people/population/national-state-and-territory-population/latest-release#states-and-territories>.

⁴ Carers Australia, "Caring for Others and Yourself: The 2021 Carer Wellbeing Survey," (Canberra: Centre for Change Governance and NATSEM, 2021), 16, [211011 Carer-Wellbeing-Survey Final.pdf \(carersaustralia.com.au\)](https://www.carersaustralia.com.au/wp-content/uploads/2021/11/211011-Carer-Wellbeing-Survey-Final.pdf).

⁵ Ibid.

⁶ *Carers Recognition Act 2021* (ACT) s8 (1).

⁷ ACT Government, *ACT Carers Strategy 2018-2028: First Three-Year Action Plan*, (Canberra: Government of the Australian Capital Territory, 2018), [ACT Carers Strategy 2018-2028](https://www.act.gov.au/act-carers-strategy-2018-2028).

affected. Funding to scope mental health respite is the only outstanding commitment in the Parliamentary Agreement.

Funding Proposals

Proposal 1 - Dual Diagnosis Ward

Purpose of proposal: This proposal aims to address the gaps in support for people with dual diagnosis, including those who experience mental ill health while living with a drug and alcohol dependency. The proposal seeks to establish a dual diagnosis ward in the upcoming Northside Hospital to provide comprehensive and integrated mental health, alcohol, and drug services.

MHCV appreciates that work to enhance this integration is being undertaken by the ACT Government within the Mental Health Policy and Strategy Unit and in the form of the commissioning process for the Alcohol, Tobacco and Other Drug (ATOD) services subsector. We are also pleased to hear that the Government has allocated \$220,000 for the establishment of a new service for families and carers of people affected by drug use. While we appreciate the program will be a 12-month pilot, MHCV would like to see the integration of this program within the mental health sector to target dual diagnosis assistance for carers of those affected by drug use.

Dual diagnosis is a complex and challenging issue that affects a significant number of people in the ACT. Mental ill health or ATOD dependency can exacerbate each other, leading to negative health impacts, social isolation, and stigma.⁸ Carers of people with dual diagnosis often report a lack of appropriate and accessible services, including limited navigation pathways, crisis support, and long-term care. The proposed dual diagnosis ward in the upcoming Northside Hospital will provide a much-needed service for people with comorbidity and their carers.

Impacts:

Impact description: The proposed dual diagnosis ward will provide access to appropriate services and support, improving the wellbeing of carers and those with dual diagnosis. It will reduce hospital admissions and emergency department presentations and enhance the capacity of carers to provide support and care.

Who is affected: Canberrans who experience mental ill health and live with a drug and alcohol dependency as well as their carers.

Wellbeing domain: 'Access and Connectivity' and 'Health'.

Timeframe: The proposed dual diagnosis ward is expected to have an immediate impact on the wellbeing of those affected. Long-term benefits include the reduction of pressure on the health system.

Evidence base: There is a significant need for a dual diagnosis ward in the ACT. Carers have reported gaps in supports for people with dual diagnosis, and there is a growing recognition of the importance of

⁸ R. E. F. Kingston, C. Marel, and K. L. Mills, "A systematic review of the prevalence of comorbid mental health disorders in people presenting for substance use treatment in Australia," *Drug and Alcohol Review* 36, no. 4 (2017), 534, <https://pubmed.ncbi.nlm.nih.gov/27786426/>.

integrated mental health and alcohol and drug services. According to the Royal Australian and New Zealand College of Psychiatrists, the overall consensus of research evidence and clinical expertise is that psychiatric or addiction-focused treatments on their own are not sufficient to manage comorbid mental health and addiction.⁹ This disconnect is regularly identified as an impediment to effective referral and holistic treatment. Evidence suggests that for many people with co-occurring conditions treating substance use and other mental illness concurrently within the same service is the best way to improve outcomes for people with comorbidities.¹⁰

Likewise, evidence from other Australian jurisdictions demonstrates that dual diagnosis services can reduce hospital admissions, improve mental health and substance use outcomes, and enhance the quality of life for people with dual diagnosis and their carers. Evaluation of the Victorian Dual Diagnosis Initiative (VDDI), the cross-sector (Alcohol and Drug, Mental Health Community Support and Clinical Mental Health) initiative funded by the Victorian Department of Health, found that a focus of dual diagnosis strategies and policies have reduced the rigid demarcation that existed between each of the sectors, easing access to services for community members in need.¹¹ In addition to this, the Victorian Government allocation of \$9.42 million to expand the Westside Lodge dual diagnosis unit at Sunshine Hospital (operated by Western Health) outlined the following project benefits; improved access to services, new construction jobs (with the peak of construction expecting to create and sustain around 28 construction industry jobs), and relieving pressure on the health system.¹² A dual diagnosis ward in the upcoming Northside hospital, like that of the Victorian Westside Lodge, will provide similar advantages to the wellbeing of the ACT community.

Proposal 2 – Ongoing funding for mental health respite

Purpose of proposal: MHCV asks that the Government actively consider the huge gap in funding for respite to mental health carers, who often experience burnout, relationship breakdown, and poor health outcomes due to a lack of rest and support. Due to the nature of mental illness, mental health carers are met with challenges which require respite to be specialised.

Given these specialised needs, availability and accessibility of mental health respite services has been expressed by carers as an urgent gap to be addressed. The introduction of the National Disability Insurance Scheme (NDIS) has resulted in the discontinuation of many mental health-specific respite services that were previously available under the Department of Social Services-funded Mental Health Respite: Carer Support (MHR:CS) program.¹³ Other respite services have transitioned to consumer-focused models that are now

⁹ Australian Government, Productivity Commission, *Inquiry into Mental Health*, (Royal Australian and New Zealand College of Psychiatrists: Submission no. 1200), 4, [Submission 1200 - Royal Australian and New Zealand College of Psychiatrists \(RANZCP\) - Mental Health - Public inquiry \(pc.gov.au\)](#).

¹⁰ Australian Government, Productivity Commission, *Inquiry into Mental Health*, (Victorian Alcohol and Drug Association: Submission no. 1205), 2-3, [Submission 1205 - Victorian Alcohol and Drug Association \(VAADA\) - Mental Health - Public inquiry \(pc.gov.au\)](#).

¹¹ "Dual Diagnosis Initiative," Primary Health Network – Eastern Melbourne, 2021, [Dual Diagnosis | Eastern Melbourne PHN \(emphn.org.au\)](#).

¹² "Westside Lodge dual diagnosis unit expansion," Victorian Health Building Authority, 2022, [Westside Lodge dual diagnosis unit expansion | VHBA](#).

¹³ Carers NSW, "Repositioning respite within consumer directed service systems," (Sydney: Carer Respite Alliance, 2021), 21, [Repositioning-respite-within-consumer-directed-service-systems.pdf \(carersnsw.org.au\)](#).

funded through the NDIS or Department of Health.¹⁴ These services, such as Step-up, Step-down accommodation, and limited day programs for consumers, may allow carers to take a break from their responsibilities. However, specific activities and supports for carers are not funded and are determined by the service provider. Although limited federal funding for respite is provided by the Commonwealth Psychosocial Support Program (set to cease in June 2023) and the Carer Gateway, current mental health respite provision is inadequate to support demand. Unfortunately, the consumer-focused models post-NDIS do not consider the additional challenges faced by mental health carers, particularly in situations where the person they care for has limited understanding of their condition or is unwilling to participate in services. In such cases, services that provide a respite outcome are not accessible for carers without the participant's consent. While the NDIS has made positive strides in addressing psychosocial disability in the recent years, there continues to be gaps in respite service provision that must be urgently addressed.

The proposal seeks to ensure that the upcoming budget, and all future budget, consider funding packages that provide a range of respite services, including; day program-care, institutional respite, and in-home respite, as well as community-based rehabilitation programs for care recipients and capacity building support groups for carers. Particularly, MHCV would like to highlight the considerations to be made when addressing time and safety through respite modelling, both domains which continue to be of concern for mental health carers.

Impacts:

Impact description: Respite will support the recovery of care recipients and operate as a protective factor by improving family relationships, preventing carers from burnout and detrimental stress, and averting family crises and conflicts. It will also minimise the risk of carer burnout, relationship breakdown, and poor health outcomes. The proposed range of respite services will provide a much-needed break for carers, allowing them to rest and recover, pursue their own interests, and maintain their own physical and mental health.

Who is affected: Mental health carers and care recipients.

Wellbeing domain: 'Time', 'Safety', 'Access and Connectivity' and 'Health'.

Timeframe: The proposed range of respite services is expected to have an immediate impact on the wellbeing of those affected.

Evidence base: Respite allows carers to refocus on their own minds or bodies and reengage with their wellbeing by pursuing leisure activities and socialising. Breaks likewise allowed carers to catch up on their own everyday jobs and maintain paid employment. Respite also helps the carer continue caring by minimising the risk of burnout. There is strong evidence to support the provision of respite to mental health carers, both in the domains of time and safety.

¹⁴ Ibid.

Time

Carers have less free time compared to non-carer peers. Studies show that an average Australian has 2 to 6 hours of free time per day.¹⁵ Lone parents have the least amount of free time, while childless and two-earner couples have the most. Mental health carers rarely get the recommended 2.5 hours¹⁶ of free time each day. Over one-third of Australian carers spend 40 or more hours per week caring for someone, while also completing some form of employment or study.¹⁷ Providing carers with respite recognises that they need time to rest and enjoy free time.¹⁸ In-home support services, short-term stay, and day programs in community-based rehabilitation programmes can alleviate carer time barriers and support the consumer. Research shows that respite allows carers to refocus on their own well-being by pursuing leisure activities and socialising.¹⁹ Breaks also allow carers to catch up on their own everyday jobs and maintain paid employment, thereby minimising the risk of burnout.²⁰

Safety

Mental health carers have expressed that they have often feel unsafe in their caring role due to the episodic and unpredictable nature of serious mental illness. Understandably, violence or abuse from care recipients experiencing serious mental illness can substantially decrease carer wellbeing across all indicators. Labrum et al.'s review states that emotional responses to these occurrences included feelings of fear, powerlessness, self-blame, and desensitisation.²¹ The 2021 MHCV Biannual Survey found that of all the mental health carers in the ACT that responded, around half had felt unsafe in their caring role over the last 18 months.²²

This is a significant to note as mental health service policies move away from institutionalisation²³ – leaving the majority of caring responsibilities for people with mental ill health on their carers. For example, the PACER model presents an alternative to hospitalisation or incarceration in the first instance, but also leaves mental health carers in domestic situations of aggression and violence without the requisite training or skills to deal with them. The ACT PACER (Police Ambulance Clinician Early Response) performance report between

¹⁵ Robert E. Goodin et al., "The Time-Pressure Illusion: Discretionary Time Vs. Free Time," *Social Indicators Research* 73, no. 1 (2005), 51, <https://www.jstor.org/stable/27522213>.

¹⁶ Marissa Sharif, Cassie Mogilner, and Hal Hershfield, "The Effects of Being Time Poor and Time Rich on Life Satisfaction," SSRN (2018), <http://dx.doi.org/10.2139/ssrn.3285436>.

¹⁷ "Disability, Ageing and Carers, Australia: Summary of Findings," Australian Bureau of Statistics, publication October 2019 (accessed March 2023), [Disability, Ageing and Carers, Australia: Summary of Findings, 2018 | Australian Bureau of Statistics \(abs.gov.au\)](https://www.abs.gov.au/Disability-Ageing-and-Carers-Australia-Summary-of-Findings-2018).

¹⁸ Yun-Hee Jeon, Henry Brodaty, Colleen O'Neill, and Jon Chesterson "'Give Me a Break'- Respite Care for Older Carers of Mentally Ill Persons," *Scandinavian Journal of Caring Sciences* 20, no. 4 (2006), 428, <https://doi-org/10.1111/j.1471-6712.2006.00423.x>

¹⁹ David Evans, "Exploring the Concept of Respite," *Journal of Advanced Nursing* 69, no. 8 (2013), 1909, <https://doi-org/10.1111/jan.12044>.

²⁰ Ibid.

²¹ Travis Labrum, M. A Zingman, I, Nossel and L. Dixon, "Violence by Persons with Serious Mental Illness Toward Family Caregivers and Other Relatives: A Review," *Harvard Review of Psychiatry* 29, no.1 (2021), 17, <https://doi.org/10.1097/HRP.0000000000000263>

²² Mental Health Carers Voice, "Filling the Cup Back Up – 2022 ACT Mental Health Carers Survey Report," (Canberra: Carers ACT, 2022), 6, <https://mhcv.org.au/wp-content/uploads/2022/07/2022-MHCV-Survey-Report.pdf>.

²³ See generally Eric D. Johnson, "Differences among Families Coping with Serious Mental Illness: A Qualitative Analysis," *American Journal of Orthopsychiatry* 70, no. 1 (2000): 126-134, <https://doi.org/10.1037/h0087664>; K. Harvey et al., "A Review of Instruments Developed to Measure Outcomes for Carers of People with Mental Health Problems," *Acta Psychiatrica Scandinavica* 117, no. 3 (2008): 164-176, <https://doi-org/10.1111/j.1600-0447.2007.01148.x>.

December 2019 and June 2020 noted that over 77% of people experiencing acute mental health crises remained in the community after engaging with the emergency service.²⁴ Specialised emergency respite would allow the care recipient to receive mental health care while also giving carers the opportunity to distance themselves from the crisis situation and recuperate. Research shows that respite not only supports the recovery of the care recipient but also operates as a protective factor by improving family relationships, preventing carers from burnout and detrimental stress, and averting family crises and conflicts.

Conclusion: Engagement and Evaluation

Collaboration and Engagement: As the peak body for mental health carers, the aforementioned proposals have been found upon continuous engagement and consultation with carers, including those within the MHCV Advocacy and Policy Advisory Group (APAG). Acknowledging that both proposals are in their preliminary stages, MHCV expects co-design going forward between the Canberra Health Directorate and Carers ACT, MHCV, and other peak bodies/community partners.

Measures of success: MHCV and Carers ACT will work collaboratively with the ACT Government and relevant stakeholder to develop approved performance indicators, implementation, and evaluation plans.

The funding would achieve the following outcomes:

- 1) Embedding the principles of the *Carers Recognition Act 2021* in service planning within the ACT
- 2) Improvement in the overall sense of wellbeing of carers as measured through the annual administration of the Personal Wellbeing Index
- 3) Significant reduction in stress, improvement in wellbeing and capacity to continue in the caring role
- 4) An increase in the perception of carers that Canberra is a community that cares for carers
- 5) Carers report feeling more valued and acknowledged in their caring role
- 6) The views of carers are considered in the planning and delivery of services that enhance the health, wellbeing and inclusion of them and the people they care for

The most significant outcomes achieved through the proposals will be in the following wellbeing indicators:


Domain	Indicator	Measures
Personal Wellbeing	Life Satisfaction	<ul style="list-style-type: none"> • Personal Wellbeing Index (collected by Carers ACT and others)
Access and Connectivity	Access to Services	<ul style="list-style-type: none"> • Access Canberra Customer Satisfaction Survey
	Inclusive Access	<ul style="list-style-type: none"> • Carer engagement annual reports as required by the <i>Carers Recognition Regulation 2021</i> (ACT) • Biannual Mental Health Carers Voice survey report • Biannual Carers Survey National Network of Carers Associations
Governance and Institutions	Feeling that voice and perspective matter	<ul style="list-style-type: none"> • Living Well in the ACT Region Survey • Annual survey of carers through Carers ACT

²⁴ ACT Ambulance Service, ACT Policing, and Canberra Health Services, “PACER Performance Report” (Canberra: unpublished, 2021), 8.

Health	Overall health	<ul style="list-style-type: none"> • ACT General Health Survey • Carers ACT STAR Outcome Measure on Health
	Mental health	<ul style="list-style-type: none"> • ACT General Health Survey • Carers ACT DASS Scores for carers accessing counselling
	Getting enough sleep	<ul style="list-style-type: none"> • ACT General Health Survey
	Access to GP Services	<ul style="list-style-type: none"> • Living Well in the ACT Region Survey • Biannual Carers Survey National Network of Carers Associations
	Access to Mental Health Services	<ul style="list-style-type: none"> • Living Well in the ACT Region Survey
Identity and belonging	Connection to Canberra	<ul style="list-style-type: none"> • Living Well in the ACT Region Survey
	Sense of belonging and inclusion	<ul style="list-style-type: none"> • Living Well in the ACT Region Survey
Social Connection	Levels of loneliness	<ul style="list-style-type: none"> • Living Well in the ACT Region Survey
	Sense of social connection	<ul style="list-style-type: none"> • Living Well in the ACT Region Survey
Time	Unpaid work including caring	<ul style="list-style-type: none"> • Living Well in the ACT Region Survey • Carers ACT data
	Quality of time	<ul style="list-style-type: none"> • Living Well in the ACT Region Survey • Carers ACT data

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