Let’s Care for Our Carers

Mental Health Carers Australia Federal Election Policy Platform
In the lead up to the federal election, Mental Health Carers Australia is asking all political parties and independents to commit to the following for unpaid mental health carers:

1. Remove barriers to mental health carers’ access to education, training, employment and volunteering by abolishing the ‘25 hour rule’ in the Carer Payment

2. Ensure that mental health carers have timely access to essential respite services

3. Improve the national carer support service so that it meets the needs of mental health carers

4. Give mental health carers a reliable and trusted national voice
Mental Health Carers Australia (MHCA) is the only national advocacy group solely concerned with the well-being and promotion of mental health carers. It is a coalition of seven state and territory organisations and one national organisation, concerned with the needs of family and friends who support someone living with mental illness. The members are: HelpingMinds (Western Australia), Mental Health Carers Tasmania, Tandem (Victoria), Arafmi (New South Wales), Arafmi (Queensland), Mental Illness Fellowship Northern Territory and Mind Australia.

Mental Health Carers Australia advocates for systemic change to ensure the unpaid work of mental health carers and families is recognised, and policies and services that meet their unique challenges and needs are developed. MHCA works closely with government at all levels, other service providers, and advocacy organisations such as Carers Australia and Mental Health Australia.

Mental Health Carers Australia firmly believes that mental health carers must be valued in their own right, and that policy responses that meet mental health carers specific and unique needs are essential.
Mental Health Carers: a snapshot

A mental health carer is a person who provides regular and sustained unpaid care to a friend or family member with a mental illness.

Unpaid mental health carers play an essential role in Australian society. Not only do they provide ongoing emotional support, but often find themselves having no option but to also provide extensive social and practical support in the absence of support services.

More than a third of mental health carers find themselves responsible for providing over 40 hours of care each week, often due to government support services being inappropriate, inaccessible, underfunded or unavailable.

What do we know about unpaid mental health carers in Australia?

- There are over 240,000 Australians who provide unpaid care to a friend or family member who is experiencing mental illness.
- Over 54,000 of these carers are ‘primary mental health carers’ who provide the most unpaid assistance to a person they care for.
- The value of the unpaid work done by mental health carers is worth $14.3 billion to the economy annually.
- Mental health carers face significant barriers to retaining paid work, with between 45–56% of working age primary mental health carers having reduced their hours or left employment due to their caring role.
- Young mental health carers have reduced educational and employment opportunities, with only 71.4% of carers aged between 15–24 studying or in paid work, compared to 91.3% of their non-carer counterparts.
In the absence of adequate and appropriate support services, family members and friends are increasingly meeting the demand for intensive and complex care for people with mental illness. Mental health carers often face different challenges to those faced by other carer cohorts, and consequently, have their own unique support needs. Mental illness has a younger age of onset than most physical health conditions such as cardiovascular, musculoskeletal and neurological disorders. Mental health carers also tend to provide high levels of emotional and behavioural support to the person they care for, making up on average 67.9% of their caring role\(^1\). Providing these supports, and a range of other day-to-day supports, long-term can have a significant impact on their economic security, health and wellbeing and education.

Mental health carers have been significantly impacted by major reforms to Commonwealth Government funded mental health services over the last few years. These reforms have seen services shift from targeted and specialist mental health support services towards generalist disability solutions. This trend is illustrated by two major reforms to the delivery of community-based mental health services: The National Disability Insurance Scheme (NDIS) and the Integrated Carer Support Service (ICSS).

Among other issues, many mental health carers are experiencing a significant reduction in the support services available to them.

Without adequate and appropriate support, carers can see a reduction in their own health and wellbeing, with some becoming at risk of developing their own mental health conditions\(^2\). Not only does this lack of support have consequences for the carer, it can also have negative consequences for the person they care for, particularly if it results in the carer being no longer able to perform their caring role\(^3\).

If their carer is no longer able to provide them with ongoing support, the person with mental illness can become more at risk of hospitalisation, homelessness and suicide. These impacts in turn, flow on to the federal, state and territory governments with cost blow outs in health, justice, housing and homelessness, and addiction services\(^4\).

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Looking into the future, Australia's need for informal care will outstrip the supply within the next ten years\(^5\). The looming deficit of informal care already has significant financial implications for the Australian Government. It has been estimated that $13.2 billion annually would be required each year from the government’s health and community sector to replace the work carried out by unpaid mental health carers in Australia if they could no longer undertake their caring role\(^6\).

Mental Health Carers Australia’s four proposed changes will help ensure that carers who wish to continue in their caring roles are supported to sustain these roles long-term. Given the potential financial implications of a reduction in available informal care for the Australian Government, implementing these four changes is in the interest of both carers and their families, and the federal government.


\(^6\)Diminic op.cit.
Let's Care for Our Carers
One: Remove barriers to mental health carers’ access to education, training, employment and volunteering by abolishing the ‘25-hour rule’ in the Carer Payment

Research commissioned by Mind Australia in 2018 shows that:

- Mental health carers are significantly less likely to be employed. 42.3% of working age mental health carers were not employed, compared to 24.0% of working age non-carers.
- There is a direct correlation between mental health caring and workforce participation, with between 45-56% of working age primary mental health carers having reduced their hours or left employment due to their caring role.
- Young mental health carers aged between 15-24 years were less likely to be in employment or education. 28.6% of young mental health carers were not employed nor studying, compared to 8.7% of non-carers.
- Primary mental health carers have lower levels of tertiary education, with 54.5% of primary mental health carers having a highest level of education as Year 12 or less, compared to 45.85% of all Australians.
Mental health carers face considerable barriers to participating in the workforce, education and training. The intense and episodic nature of mental illness, combined with a lack of adequate replacement care systems available for the person they care for, make it difficult for carers to balance employment, education and training with their caring roles. This is further compounded for those wanting to enter or remain in the workforce by inflexible or unsupportive workplace culture and design.

Another barrier for carers who currently rely on the Carer Payment from Centrelink for income can be its restriction on a carer’s participation in work and education to 25 hours per week (including travel time). For carers who need to provide care on an unpredictable or episodic basis, this can create challenges when carers need to transition in and out of work or education as their caring role intensifies or reduces. Carers can also find this rule disincentivises them pursuing new educational or employment opportunities as they come at a significant financial risk to them and their families.

Lower levels of employment, education and training for mental health carers, compared to their non-carer counterparts, can have a range of social, economic and health impacts on mental health carers. The financial impacts of limited participation in the workforce are both immediate and cumulative, including lower income, disrupted careers and lower savings and superannuation. Other negative effects of unemployment can include reduced social networks and poorer health outcomes. Reduced participation in the workforce also has negative consequences for government, including lower tax revenue, increased spending on health and income supports.
While Mental Health Carers Australia understands that removing all the barriers faced by mental health carers in regard to employment, education and training is a long-term, multi-faceted project, one easy, common sense change the Australian Government should make now is to abolish the ‘25-hour rule’ in the Carer Payment.

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Two: Ensure that mental health carers have timely access to essential respite services

Respite services give mental health carers an opportunity to take a break from their caring responsibilities by providing essential supports to the person they care for. Respite services supports can include: paid in-home care, supported accommodation and community-based care centres.

Respite provides carers with a much-needed break to pursue their own needs or needs of other family members. For many carers, this opportunity to look after their own wellbeing is essential to sustaining their caring role over the long-term. It can also help them retain their employment, pursue further studies and maintain social and familial relationships.

For some mental health carers, in the absence of respite, they would be simply unable to spend a night away from the person they care for.
Prior to the introduction of the National Disability Insurance Scheme (NDIS), mental health carers were able to access respite through a national funding program, called Mental Health Respite: Carer Support. Along with a range of other services, this program provided carers with temporary relief from their caring responsibilities through planned short-term respite.

The Mental Health Respite: Carer Support program is now closing, with its funding rolling into the NDIS. Modelling undertaken by Mental Health Australia in 2017 identified that the Mental Health Respite: Carer Support program assisted over 40,000 carers in 2013-2014. When the NDIS is fully rolled out, it is anticipated that it will fund supports for 64,000 people with a psychosocial disability. However, only around 1.3% of all NDIS participants are currently receiving short-term accommodation support (respite). If this rate continues, at full roll out this will equate to an estimated 830 people with a psychosocial disability receiving short-term accommodation support (respite) through the NDIS.

Even if additional NDIS funded supports that could be considered carer respite, such as overnight in-home care, are added to this estimate, it is still highly likely that the respite available under the NDIS will fall significantly short of need.

To further compound this issue, the NDIS has significant shortfalls in its recognition of mental health carers and the important role they play in supporting those eligible for the scheme. Eligible NDIS participants are given individualised funding plans. While the NDIS has admirable aims for delivering individualised support to the participant, it is not always compatible with meeting the support needs of their carer.

In the case of respite, while a carer might identify their need for respite, respite might not be a priority for the participant: meaning that these carers will also be unable to access respite.

Mental Health Carers Australia anticipates that a significant number of mental health carers will struggle to get the respite they need.
**Actions needed**

1. The Department of Social Services (DSS) to work with the NDIA, state and territory governments and other stakeholders to develop and implement a plan to meet this shortfall. Including, undertaking work to:
   - Quantify the amount of unmet need in relation to respite services for mental health carers;
   - Understand how the shortfall will impact both those potentially eligible for the NDIS and those left out of it.

2. The NDIA to adopt recommendation 9.6 of the 2017 *Productivity Commission Inquiry into the National Disability Insurance Scheme (NDIS) Costs*\(^1\). Recommendation 9.6 includes the following changes:
   - Ensuring planners take into account the amount of respite care that is reasonable and necessary under an individualised support package, based on the amount of informal care that is expected to be performed by informal carers;
   - Labelling short-term accommodation supports provided in participants’ plans in a way that makes it clear these supports can be used for respite;
   - Better informing participants and their informal carers that core supports provided in individuals’ support packages can be used to fund additional in-home care or support in shared facilities to provide respite.

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\(^9\) David McGrath Consulting, 2017, The implementation and operation of the psychiatric disability elements of the National Disability Insurance Scheme: A recommended set of approaches


\(^11\) Smith-Merry, et al. op. cit.

Let's Care for Our Carers
Three: Improve the national carer support service so that it works for mental health carers

The federal government is introducing a new standardised approach to providing supports for all cohorts of unpaid carers, called the Integrated Carer Support Service (ICSS). The ICSS includes a website, the Carer Gateway launched in 2015, and a national contact centre.

It will also include, to be rolled out in the near future, sixteen local service providers, called Regional Development Partners (RDPs). These RDPs will be spread across Australia and will coordinate and deliver services for carers.
Issue

Mental Health Carers Australia has two concerns with the proposed approach of the Integrated Carer Support Service.

Firstly, the ICSS represents a significant shift away from face-to-face support, with its focus on over the phone and online support. While many carers have regular access to the internet and feel confident in their computer literacy levels, there is still a population of carers who would be excluded from online services (Department of Social Services). This can be seen reflected in the department’s own research that states that only 57% of carers were very likely or definitely likely to access the Carer Gateway website\(^\text{13}\). Given this, it is vital the ICSS strikes the right balance between face-to-face, over the phone and online support services for carers.

Mental Health Carers Australia is also concerned about the ICSS’s ability to meet the unique support needs of unpaid mental health carers. The one-size fits all design of the ICSS appears to have not adequately taken into account the different and diverse needs of mental health carers, hampering their ability to undertake their vital care work and negatively impacting their health and wellbeing.
Mental Health Carers Australia suggests that the following improvements be made to the ICSS:

1. Develop and implement a specialist mental health gateway in the scheme, including within the design and the roll out of the RDPs.
2. That DSS commit to a full review of the ICSS and its impact on mental health carers after the conclusion of the first round of 5-year RDP contracts. This review needs to involve service and advocacy organisations working with mental health carers.
Let's Care for Our Carers
Four: Give mental health carers a reliable and trusted national voice

Mental health services at the national level are going through a period of profound change. The shift to individualised funding packages with the NDIS, and the new approach to carer support services through the ICSS, will fundamentally transform how mental health support services are delivered to both consumers and carers.

Mental Health Carers Australia members, individually and as a coalition, are being called on to participate in a range of detailed, rapidly moving policy formulation processes and debates. Mental Health Carers Australia’s ability to be a strong voice for mental health carers is stifled by its lack of resources.
Due to Mental Health Carers Australia’s resource deficit, mental health carers lack a consistent, organised voice in national policy debates around changes to service delivery that directly impact them and their family. Mental Health Carers Australia’s effectiveness and strategic influence would be greatly improved by having access to the necessary resources to function as a formalised national peak body representing unpaid mental health carers.

Creating a national peak body to represent mental health carers would assist government policy makers to better coalesce the views of service delivery and advocacy bodies working with unpaid mental health carers. It would also give government a means to extend the reach of its policy consultation processes in this area.

Mental Health Carers Australia strongly believes that better reflecting the experiences of mental health carers will not only improve the situation of this particular cohort of carers but also lead to better outcomes for the people they care for.

A resourced, national peak body for mental health carers is essential in:

- Ensuring the new ICSS and the new psychosocial disability stream of the NDIS is meeting the unique needs of mental health carers;
- Improving employment, education and training outcomes for mental health carers, including amplifying the voices of carers in the upcoming Productivity Commission inquiry into the role of mental health in the Australian economy;
- Ensuring that *A Practical Guide for Working With Carers of People With a Mental Illness* becomes embedded in the accreditation standards of all mental health service providers, NDIA planners and LACs;
- Contributing carers’ voices to the planning of Commonwealth, and state and territory, mental health service improvements across jurisdictional divides.
**Actions needed**

That the federal government provides $450,000 per annum in grants to Mental Health Carers Australia over three years to ensure mental health carers are represented at this critical point in national system design.

This funding would provide Mental Health Carers Australia with the resources it needs to be a strong voice for mental health carers in national policy debates and system design, as well as establishing itself as a national peak body.