



Carers Victoria – Initial Submission

**Royal Commission into
Victoria's Mental Health System**

July 2019

AN AUSTRALIA THAT VALUES AND SUPPORTS ALL CARERS

ABOUT CARERS VICTORIA

Carers Victoria is the state-wide peak organisation representing people who provide care. We represent more than 736,600 family carers across Victoria – people caring for someone with a disability, mental illness, chronic health issue or an age-related condition.

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

Carers Victoria is a membership-based organisation. Our members are primarily family carers, who play an important role in informing our work, contributing to advocacy and strategic aims, and distributing information more widely to other carers.

This policy paper was prepared by Carers Victoria's Policy Team.

© Carers Association Victoria 2019

This work is copyright. Apart from any use as permitted under the *Copyright Act 1968*, all other rights are reserved. Requests and inquiries concerning reproduction and rights should be addressed to the Copyright Officer, Carers Victoria, PO Box 2204, Footscray, Victoria, 3011.

For information contact:

Scott Walker

Chief Executive Officer

Carers Victoria

Telephone: [REDACTED]

Facsimile: [REDACTED]

Email: [REDACTED]

Website: www.carersvictoria.org.au

Table of Contents

About Carers Victoria.....	2
Executive Summary.....	4
Recommendations.....	5
Introduction.....	6
Victorian Carer Strategy 2018-22.....	7
The impacts of caring.....	7
Carers can be consumers too.....	9
Supporting the mental health of carers.....	9
Metropolitan and Regional similarities and differences.....	11
Young Carers.....	12
LGBTIQA+ Carers.....	13
Older Carers.....	14
Carers, family violence and mental health concerns.....	14
Sustaining the provision of care and employment.....	15
References.....	17

Executive Summary

Carers Victoria welcomes the opportunity to contribute to the Royal Commission into Victoria's Mental Health System (Royal Commission). Carers Victoria has chosen to focus its submission on the mental health and wellbeing of Victoria's 736,600 unpaid family and friend carers.

One in eight Victorians is an unpaid family or friend carer. It is critical the Royal Commission recommendations include measures and resources to improve the mental health of Victorian carers.

- Carers need support for their own mental health. A majority of carers (56%) are estimated to experience at least moderate depression and one fifth severe depression, as well as experiencing high levels of anxiety, psychological distress and lower perceptions of self-efficacy and personal well-being.
- Consumers of mental health services may also have care responsibilities. Consumers need to be asked about their care responsibilities and how this impacts on their mental health during assessment and review.
- Carers and consumers need support to maintain their care relationship as outlined in the Carers Recognition Act 2012. Implementation of the Victorian Carer Strategy 2018-22 will help to improve carer support through the five priority areas:
 - Carers have better health and wellbeing.
 - Carers are supported in school, study and work environments.
 - Carers can access support and services that meet their needs.
 - Carers have less financial stress.
 - Carers are recognised, acknowledged and respected.

Recommendations

- Improved access to carer needs assessment within mental health services and/or screening to identify and refer carers to appropriate carer support services.
- Improved access to evidence-based early intervention programs for carers starting out in the carer role to mitigate some of the negative mental health impacts of caring.
- Implementation of the Chief Psychiatrist's Guideline 'Working Together with Families and Carers' must become standard practice in mental health services across Victoria.
- Mandated training for staff of mental health services on the impact of mental illness on families, and the care responsibilities of children and young people.
- Mandated training for teachers and school support staff on the impact of mental illness on families, and the care responsibilities of children and young people.
- Carers to be asked if they identify as LGBTIQ+ and for mental health services to promote their support of LGBTIQ+ relationships and communities.
- Mental health services to promote the process to become a 'nominated person' and to discuss this with consumers and carers.
- Specific services for carers aged 65 and over to assist them to plan for the future care of their relative or friend with mental illness after the carer's death or incapacity.
- Implementation in all mental health services of the Chief Psychiatrist's guideline and practice resource: family violence.
- Mandate employer education on understanding mental illness and implementing flexible employment practices to accommodate the particular needs of mental health carers.

Introduction

Carers Victoria welcomes the opportunity to contribute to the Royal Commission into Victoria's Mental Health System (Royal Commission). Carers Victoria has chosen to focus its submission on the mental health and wellbeing of Victoria's 736,600 unpaid family and friend carers.

Australian and international research has documented the positive and negative aspects of caring and identified mixed effects. Studies have found that carers report positive aspects of caring, such as companionship, fulfilment, enjoyment and satisfaction, as well as the negative effects on psychological health, such as depression, anxiety and burden.¹ ²A key study in Australia in 2007 identified carers as having 'the lowest collective wellbeing of any group we have yet identified'.³

Carers make a \$15 billion contribution to the Victorian economy each year through support provided to people with care needs.⁴ Carers can experience significant personal and financial costs through providing care. Carers can lose \$50,000 - \$60,000 in lost superannuation for a 10-15-year period out of the workforce.⁵ The weekly median income of a primary carer is \$520, which is 42 per cent lower than a non-carer.⁶

Given their positive contribution to the lives of the people they care for and to the economy, it is unfair carers do not receive the mental health support they require to continue in the caring role.

One in eight Victorians is a carer. It is critical the Royal Commission consider the actions required to improve the mental health of carers. When making recommendations the Royal Commission must also consider potential indirect impacts on carers. Resources need to be made available to support the health and wellbeing of carers in line with the priorities of the Victorian Carer Strategy 2018-22.

¹ Bauer, J.M., and Sousa-Poza, A, 'Impacts of Informal Caregiving on Caregiver Employment, Health, and Family', *Journal of Population Ageing*, 8(3):113-45, 2015, doi: 10.1007/s12062-015-9116-0 in Hill, T., Broady, T, 2019, *Understanding the social and emotional needs of carers: Final report (SPRC Report 2/19)*. Sydney: Social Policy Research Centre, UNSW Sydney, <http://doi.org/10.26190/5c59202697201>, p.14.

Bauer, J.M., and Sousa-Poza, A, 'Impacts of Informal Caregiving on Caregiver Employment, Health, and Family', *Journal of Population Ageing*, 8(3):113-45, 2015, doi: 10.1007/s12062-015-9116-0 in Hill, T., Broady, T, 2019, *Understanding the social and emotional needs of carers: Final report (SPRC Report 2/19)*. Sydney: Social Policy Research Centre, UNSW Sydney, <http://doi.org/10.26190/5c59202697201>, p.14.

³ Cummins, R., Hughes, J., Tomin, A., Gibson, A., Woerner, J., and Lai, L. (2007). *The Australian Unity Wellbeing Index, Survey 17.1. The Wellbeing of Australians-Carer Health and Wellbeing*, Deakin University, Australian Unity and Carers Australia, Melbourne in Hill, T., Broady, T, *Understanding the social and emotional needs of carers: Final report (SPRC Report 2/19)*. Sydney: Social Policy Research Centre, UNSW Sydney, 2019, <http://doi.org/10.26190/5c59202697201>, p. 14.

⁴ Deloitte Access Economics, 'The economic value of informal care in Australia in 2015', <https://www.carersaustralia.com.au/storage/access-economics-report3.pdf>.

⁵ Nepal, B., Brown, L., Ranmuthugala, G. and Percival, R., 2008. Lifetime health and economic consequences of caring: Modelling health and economic prospects of female carers in Australia. Commonwealth Financial Planning, Commonwealth Bank of Australia, pp 27.

⁶ Carers Victoria, 2017. Developing a Victorian Carer Statement, pp 15.

Victorian Carer Strategy 2018-22

In July 2018 the Andrews Labor Government launched Victoria's first whole-of-government Carer Strategy 2018-22. The Strategy sets out a framework to better recognise and support carers. The Strategy outlines ways carers, peak organisations, service providers and communities will work with the State Government to address five key priorities. These five priorities are:

1. Carers have better health and wellbeing
2. Carers are supported in school, study and work environments
3. Carers can access support and services that meet their needs
4. Carers have less financial stress
5. Carers are recognised, acknowledged and respected.

Carers Victoria is committed to working with the Victorian Government to achieve these objectives. These objectives, individually and collectively, will all improve the mental health of carers.

Within the context of these priorities Carers Victoria supports the Victorian Auditor-General's Office report *Access to Mental Health Services*. Carers Victoria particularly welcomes recommendation 5:

We recommend that the Department of Health and Human Services: resolve the known catchment area issues of misaligned boundaries that prevent people from accessing services.⁷

Having consistent catchment areas across health services will make it easier for carers to navigate service systems.

The impacts of caring

The World Health Organisation (WHO) defines mental health as: 'a state of well-being in which an individual realizes his or her own abilities, can cope with the normal stresses of life, can work productively and is able to make a contribution to his or her community'.⁸

Carers experience poorer mental health outcomes compared to people who do not care,^{9,10} and there is increased risk of mental illness among sibling and child carers.¹¹

⁷ Victorian Auditor-General's Office, *Access to Mental Health Services* <https://www.audit.vic.gov.au/report/access-mental-health-services?section=33104--audit-overview#chapter-4>, March 2019, accessed 07.06.2019.

⁸ World Health Organisation, <http://www.who.int/news-room/fact-sheets/detail/mental-health-strengthening-our-response>, in Hill, T., Broady, T, Understanding the social and emotional needs of carers: Final report (SPRC Report 2/19). Sydney: Social Policy Research Centre, UNSW Sydney, 2019, <http://doi.org/10.26190/5c59202697201>

⁹ Australian Bureau of Statistics, 2012 Survey of Disability, Ageing and Carers Australia, 2013, Cat. No. 4430.0

¹⁰ Carers NSW, 2012, Biennial Carer Survey

¹¹ Robinson E., Rodgers B., & Butterworth P., 2008 'Family relationships and mental illness - Impacts and service responses' in Australian Family Relationships Clearinghouse – AFRC Issues, Number 4, 2008.

Carers are more likely to have lower socio-economic status and high levels of isolation and stress,¹² with prolonged stress and grief characteristic of the caring role. A majority of carers (56%) are estimated to experience at least moderate depression and one fifth severe depression¹³, as well as experiencing high levels of anxiety,¹⁴ psychological distress and lower perceptions of self-efficacy and personal well-being.^{15 16}

This can remain even after care roles have ceased. Some research also suggests carers are significantly more likely to have suicidal thoughts than non-carers due to feelings of hopelessness.^{17 18}

Hill and Broady's (2019) analysis of data from the Australian Bureau of Statistics showed that:

- 'One in four (26.5%) primary carers had 'high or very high levels of psychological distress
- Nearly three quarters of primary carers (72.2%) reported that they were not satisfied due to the caring role
- Around one in ten (11.2%) carers frequently felt angry or resentful due to the caring role or had been diagnosed with a stress-related illness due to the caring role, and
- Just over one quarter of primary carers reported that they had their sleep interrupted frequently (25.3%) or frequently felt worried or depressed (27%), and around one third (35.6%) frequently felt weary or lacked energy due to the caring role'.^{19 20}

¹²Hill, P., Thomson, C., & Cass, B. (2011). The costs of caring and the living standards of carers. Department of Families, Housing, Community Services and Indigenous Affairs,).

¹³ Australian Unity Wellbeing Index: The Wellbeing of Australians – Carer Health and Wellbeing, Survey 17.1, Report 17.1, 2007, p5.

¹⁴ Watts, J. H., & Cavaye, J. (2016). Being a Former Carer: Impacts on Health and Well-Being. *Illness, Crisis & Loss*, 1054137316679992.

¹⁵ Hammond, T., Weinberg, M. K., & Cummins, R. A. (2014). The dyadic interaction of relationships and disability type on informal carer subjective well-being. *Quality of Life Research*, 23(5), 1535-1542.

¹⁶ Edwards, B., 2008, 'Section D: The mental and physical health of families caring for a person with a disability', in Edwards, B., Higgins, D., J., Gray, M., Zmijewski, N & Kingston, M., (eds), 'The nature and impact of caring for family members with a disability in Australia', Research Report 16, Australian Government, the Australian Institute of Family Studies, ACT, pgs. 56 – 64.

¹⁷ O'Dwyer, S. T., Moyle, W., Zimmer-Gembeck, M., & De Leo, D. (2013). Suicidal ideation in family carers of people with dementia: a pilot study. *International journal of geriatric psychiatry*, 28(11), 1182-1188.

¹⁸ O'Dwyer, S. T., Moyle, W., Pachana, N. A., Sung, B., & Barrett, S. (2014). Feeling that life is not worth living (death thoughts) among middle-aged, Australian women providing unpaid care. *Maturitas*, 77(4), 375-379.

¹⁹ Australian Bureau of Statistics (ABS) (2014). *Caring in the Community 2012*, Catalogue no: 44360DO001_2012, ABS, Canberra.

²⁰ Australian Bureau of Statistics (ABS) (2015). *Survey of Disability, Ageing and Carers*, TableBuilder. Findings based on use of ABS TableBuilder data.

Carers can be consumers too

Carers need support for their own mental health. Mental health services in particular, often focus on the needs of the consumer without considering that the person providing care may also require mental health support. In fact, the carer may also be a consumer of mental health services.

Carers Victoria has worked with the Department of Health and Human Services to include a question on the 'Your Experience Survey' (YES) to ask clinical mental health consumers whether they also have care responsibility for others. This is one way to encourage a shift from the black and white thinking of 'consumer' and 'carer'.

Similarly, Carers Victoria recommends the inclusion of a question in the Carer Experience Survey (CES) as to whether carers experience mental health concerns themselves.

Supporting the mental health of carers

Psychotherapy and psychoeducational interventions

Psychotherapy and psychoeducational interventions²¹ are frequently reported as having some of the most wide-ranging positive impacts and are among the most commonly used.²² Interventions aimed at improving carer knowledge and capabilities are also recognised among the most beneficial and can effectively reduce 'carer burden, distress, provide psychological support, improve coping/crisis management skills and quality of life, and increase carer self-esteem'.²³ Accessible education is most likely to be effective when it is relevant and practical.²⁴

Early intervention

Early intervention plays a vital role in risk identification, mitigation and connection to networks of support. Early and timely intervention can help people sustain caring roles, function effectively in other areas of their life and promote quality of life and wellbeing.

The Western Victorian Primary Health Network (WVPHN) identified carers at risk of mental ill-health as a priority group for early intervention and low intensity support. In 2018, Carers Victoria was commissioned to design, deliver and evaluate an evidence-based model of mental health early intervention for carers.

²¹ Consumer and Family Psychoeducation: Assessing the Evidence, D. Russell Lyman, Lisa Braude, Preethy George, Richard H. Dougherty, Allen S. Daniels, Sushmita Shoma Ghose, and Miriam E. Delphin-Rittmon *Psychiatric Services* 2014 65:4, 416-428

²² Broady, Timothy and Aggar, Christina. Carer interventions: An overview of service effectiveness [online]. *Journal of the Australasian Rehabilitation Nurses Association*, Vol. 20, No. 2, Aug 2017: 5-11.

²³ Schumacher, K., Beck, C. A., & Marren, J. M, 2006, FAMILY CAREGIVERS: caring for older adults, working with their families. *AJN The American Journal of Nursing*, 106(8), 40-49.

²⁴ Broady, Timothy and Aggar, Christina, 2017, Carer interventions: An overview of service effectiveness [online].

A theory of change informed the development of a multicomponent program titled *Mind the Step*, referencing the stepped care model of mental health and the importance of paying attention to changes in wellbeing when stepping into a caring role. The program consisted of three consecutive weekly workshops, each of three hours duration. A series of three short videos featuring three different carers was also produced to accompany and reinforce the key messages of each workshop.

There is a wealth of evidence that carers experience social isolation and poorer health outcomes than non-carers, which was echoed by carers attending the *Mind the Step* program. Evaluations found *Mind the Step* was an effective intervention that carers rated as highly valuable in gaining a sense of connection, understanding the importance of self-care, and making use of available supports and services.

Participants reported both their mental and physical health had deteriorated since taking on a caring role, and other family and friends did not well understand the impact of caring on their lives. Evaluations demonstrated that the *Mind the Step* program was broadly effective in achieving the intended outcomes of improving carers':

- Mental health and wellbeing
- Capacity to access treatment, supports and resources, and
- Sense of social connectedness.

The project also surveyed mental health practitioners. Findings highlighted that the sector's capacity to respond to carers at risk of poor mental health would be increased through improved awareness of carers and early interventions supports; and a standardised and resourced approach to screening and referral.

Mental health clinicians may recognise that carers need support. Due to resource constraints, support may be limited to provision of information on where to access carer support, rather than a mental health assessment being undertaken with the carer. Mental health clinicians advised that interactions with carers tend to be informal and are not routinely documented.

Recommendation: Improved access to carer needs assessment within mental health services and/or screening to identify and refer carers to appropriate carer support services.

Recommendation: Improved access to evidence-based early intervention programs for carers starting out in the carer role to mitigate some of the negative mental health impacts of caring

Metropolitan and Regional similarities and differences

Carers Victoria participated in community consultations for the Royal Commission in Melbourne and in Wodonga.²⁵ The phrase 'missing middle' was used widely in the Melbourne consultation and is feedback which Carers Victoria frequently receives from carers. The 'missing middle' describes the perspective of the mental health system that there are very few, or no options between General Practitioner (for initial concerns) and the Emergency Department (for crisis situations). In Wodonga, carers reported that consumers with complex needs do not have the support they require. A carer described how their relative was in the mental health inpatient unit for one year because of the lack of suitable supports outside of the hospital.

Carers in Melbourne and in Wodonga advised the impact of lack of recognition of their caring role. Carers reported decisions are routinely made without their involvement. This causes great distress for carers who want to be able to support the person they are caring for and provide further information to the treatment team.

Carers Victoria welcomed the publication of the updated Chief Psychiatrist's Guideline 'Working Together with Families and Carers' (The Guideline) in 2018. The Guideline provides a framework for Victorian mental health services to engage with families and carers at every stage people are receiving support for mental health concerns. Feedback from carers has demonstrated mixed experiences with carer inclusion in mental health services.

Recommendation: Implementation of The Guideline must become standard practice in mental health services across Victoria.

²⁵ Location changed to preserve anonymity of content used.

Young Carers

People under the age of 25 providing unpaid care to family or friends (usually parents or siblings) are referred to as young carers.

Mental Health Services

“I have a really great GP who’s like amazing and he is 100 per cent supportive and includes me in everything and even my Mum’s psychologist includes me in everything and we talk all the time. It’s just good to have a professional like her doctor to have such a close relationship and we can talk about medication she’s on. I can tell them how she is at home and about her medication – they’ll trust me 100 per cent and it’s really great they trust me and will actually listen to me.”

Examples like the one cited above show the impact of a young carer being respected and engaged by their mother’s psychologist. Unfortunately, other young carers are dismissed as not being relevant to their parent’s health. This attitude disregards the knowledge of young carers and the support they are providing.

Recommendation: Mandated training for staff of mental health services on the impact of mental illness on families, and the care responsibilities of children and young people.

Education System

Thirteen per cent of children aged 5-14 caring for a person with a mental illness do not attend school.²⁶ Young people providing care require additional support to ensure that they can continue in education and enter the workforce.

Teachers and other staff in schools frequently identify they require further support to understand the needs of young carers. Our consultations have identified that schools are a key area where caring is often not recognised and/or not responded to appropriately. This has a significant impact on educational outcomes, as well as the mental health of parents and young carers. Research from the Australian Institute of Family Studies indicates that young carers are, on average, one year behind the education standards of young people who don’t have care responsibilities.²⁷

²⁶ Diminic, S, Hielscher E and Harris M, ‘Understanding the factors associated with Australian mental health carers’ employment: summary report’, Brisbane, The University of Queensland, 2018, p. 3.

²⁷ Australian Institute of Family Studies, ‘The Longitudinal Study of Australian Children Annual Statistical Report 2016’, 2017, <https://aifs.gov.au/publications/longitudinal-study-australian-children-annual-statistical-report-2016>, accessed 02.07.2019.

Young carers have advised Carers Victoria that teachers who lacked understanding of health conditions failed to understand and acknowledge the long-term nature of their caring duties. The result was an inflexibility towards the needs of these students. Young carers consulted by Carers Victoria have indicated that teachers who understand their caring responsibilities are more flexible and that this reduces the stress experienced by young carers.

“At my last school there were only four or five teachers that if you asked for an extension, they just said no. Even if you were going through the hardest moment in that year, they still said no, wouldn’t understand, just dismissed it.”

Carers Victoria welcomed the November 2018 announcement by the Victorian Government to develop a system to better identify young carers in schools. Carers Victoria will work with the Victorian Government and The Department of Education and Training to develop this system.

Recommendation: Mandated training for teachers and school support staff on the impact of mental illness on families, and the care responsibilities of children and young people.

LGBTIQA+ Carers

LGBTIQA+ care relationships must be recognised within mental health services. The failure to do this can lead to poorer mental health outcomes for this cohort of carers.

Carers who identify as LGBTIQA+ can experience additional difficulties in the healthcare system. Carers Victoria has been advised of examples where a carer with medical power of attorney has been ignored and dismissed by a doctor; and of other carers having to deliberately deceive hospital staff about their relationship with the patient in order to maintain contact during the hospital stay.

Carers Victoria partnered with Swinburne University to research the experiences of carers of people from LGBT communities in clinical mental health settings.²⁸ This research found carers had varied experiences in the support which was provided. Whilst many interactions were positive, inconsistencies can lead people to withdraw from seeking support because of the perception of the potential for harm.

Many carers in this research were unaware that the person receiving care could make the carer a ‘nominated person’ under the *Mental Health Act 2014*.

²⁸ Martin, J., Butler, M., Muldowney, A., Aleksandrs, G., ‘Impacts of regulatory processes on the experiences of carers of people in LGBTQ communities living with mental illness or experiencing a mental health crisis’, in *Social Science & Medicine*, 2019, pp. 30-36, www.elsevier.com/locate/socscimed, accessed 01.07.2019.

By becoming a 'nominated person' carers are more likely to receive information about the person they are caring for.

Recommendation: Carers to be asked if they identify as LGBTIQ+ and for mental health services to promote their support of LGBTIQ+ relationships and communities.

Recommendation: Mental Health services to promote the process to become a 'nominated person' and to discuss this with consumers and carers.

Older Carers

More than 162,000 of Victoria's carers are aged over 65, and the average age of a primary carer is 55. Older people are more likely to have multiple care responsibilities including caring for partners, parents and children. Older parent carers in particular have grave concerns about the wellbeing of their sons and daughters living with mental illness when they are no longer able to provide care.

Recommendation: Specific services for carers aged 65 and over to assist them to plan for the future care of their relative or friend with mental illness after the carer's death or incapacity.

Carers, family violence and mental health concerns

Perpetrators and victim-survivors are multi-layered terms. Carers can be both victim-survivors as well as perpetrators of family violence. Carers ACT has produced the following typology of family violence in relationships between a carer and a person with mental health concerns:

1. Carer as a victim of violence or threats of violence, perpetrator has mental illness and has violent episodes with no evidence of power, coercion or control.
2. Carer as a victim of violence or threats of violence, perpetrator has a mental illness and has violent episodes with evidence of power, coercion and control.
3. Carer as a victim of violence or threats of violence, perpetrator is not the primary care recipient, carer and care recipient are both in danger of trauma impacts and mental ill-health.
4. Carer as a perpetrator of violence or threats of violence, care recipient has mental illness and is the victim, with or without evidence of power, coercion and control.

Additional risk attaches to people in care relationships due to the duration and intensity of serious mental illness and the efforts of family members and other supporters to try to keep the person experiencing mental illness safe. This can increase risks for the carer and is exacerbated by stigma, reluctance to engage with formal services and other factors such as social isolation and cultural and language barriers.

Barriers to help-seeking are many:

Blame: Carers and people with mental ill-health excuse the illness or the situation for the violence and see it sitting external to the person who is perpetrating. Carers rarely report concerns of violence to police or press charges but will call mental health crisis teams.

Stigma/shame: Carers and people with mental ill-health want to avoid being further stigmatised or negatively affected by disclosing the violence.

Fear: Many do not seek help because they fear the consequences of disclosure, including police involvement, financial fears, fears of the perpetrator finding out, of judgement etc.

Episodic: The violence may fluctuate with the illness/care needs further removing it from the person's identity.

Appropriate help available: Many families believe family violence interventions will force them to leave the relationship. Carers may not feel like they can leave for several possible reasons. These reasons include: the person they care for needs their support, victim-survivors with mental illness may find it harder to leave, and carers are concerned that the person they care for may become homeless if they leave.

Recommendation: Carers Victoria supports development of a greater understanding within mental health services on the impact of mental illness and family violence within care relationships. Carers Victoria supports implementation in all mental health services of the Chief Psychiatrist's guideline and practice resource: family violence²⁹ which was developed following Family Violence Royal Commission Recommendation 97.

Sustaining the provision of care and employment

Carers find it difficult to reconcile caring responsibilities with full time, part time or casual employment. This results in setbacks in career progression and financial hardship due to loss of income and superannuation.

The benefits of carer flexible workplaces are two-pronged.

1. For carers they include improved self-esteem, wellbeing and financial security.
2. For employers they include increased staff retention, improved productivity and job satisfaction of employees, which in turn reduces recruitment and training costs.

²⁹ <https://www2.health.vic.gov.au/about/key-staff/chief-psychiatrist/chief-psychiatrist-guidelines/family-violence-guideline-practice-resource>

Issues for mental health carers in employment include affiliate stigma³⁰ for close associates of people living with mental illness. This can lead to carers not disclosing their carer status for fear of discrimination. The unpredictable nature of some mental illnesses also means carers may need to take time off work at short notice, leading some employers to consider them to be 'unreliable'.

Recommendation: Mandate employer education on understanding mental illness and implementing flexible employment practices to accommodate the particular needs of mental health carers.

³⁰ Shi, Y, Shao, Y, Li, H, et al. Correlates of affiliate stigma among family caregivers of people with mental illness: A systematic review and meta-analysis. *Journal of Psychiatric and Mental Health Nursing*, 2019; 26: 49– 61. <https://doi.org/10.1111/jpm.12505>

References

- Australian Bureau of Statistics, 2012 Survey of Disability, Ageing and Carers Australia, 2013, Cat. No. 4430.0
- Australian Institute of Family Studies, 'The Longitudinal Study of Australian Children Annual Statistical Report 2016', 2017, <https://aifs.gov.au/publications/longitudinal-study-australian-children-annual-statistical-report-2016>
- Australian Unity Wellbeing Index: The Wellbeing of Australians – Carer Health and Wellbeing, Survey 17.1, Report 17.1, 2007, p5.
- Broady, Timothy and Aggar, Christina. Carer interventions: An overview of service effectiveness [online]. Journal of the Australasian Rehabilitation Nurses Association, Vol. 20, No. 2, Aug 2017: 5-11.
- Carers NSW, 2012, Biennial Carer Survey
- Carers Victoria, 2017. Developing a Victorian Carer Statement,
- Deloitte Access Economics, 'The economic value of informal care in Australia in 2015', <https://www.carersaustralia.com.au/storage/access-economics-report3.pdf>.
- Diminic, S, Hielscher E and Harris M, 'Understanding the factors associated with Australian mental health carers' employment: summary report', Brisbane, The University of Queensland, 2018
- Edwards, B., 2008, 'Section D: The mental and physical health of families caring for a person with a disability', in Edwards, B., Higgins, D., J., Gray, M., Zmijewski, N & Kingston, M., (eds), 'The nature and impact of caring for family members with a disability in Australia', Research Report 16, *Australian Government, the Australian Institute of Family Studies*, ACT, pgs. 56 – 64.
- Hammond, T., Weinberg, M. K., & Cummins, R. A., 2014, 'The dyadic interaction of relationships and disability type on informal carer subjective well-being' *Quality of Life Research*, 23(5), 1535-1542.
- Hill, T., Broady, T, 2019, *Understanding the social and emotional needs of carers: Final report (SPRC Report 2/19)*. Sydney: Social Policy Research Centre, UNSW Sydney, <http://doi.org/10.26190/5c59202697201>.
- Hill, P., Thomson, C., & Cass, B, 2011, 'The costs of caring and the living standards of carers', Department of Families, Housing, Community Services and Indigenous Affairs
- Martin, J., Butler, M., Muldowney, A., Aleksandrs, G., 'Impacts of regulatory processes on the experiences of carers of people in LGBTQ communities living with mental illness or experiencing a mental health crisis', in *Social Science & Medicine*, 2019, pp. 30-36, www.elsevier.com/locate/socscimed.

Nepal, B., Brown, L., Ranmuthugala, G. and Percival, R., 2008. Lifetime health and economic consequences of caring: Modelling health and economic prospects of female carers in Australia. Commonwealth Financial Planning, Commonwealth Bank of Australia

O'Dwyer, S. T., Moyle, W., Zimmer-Gembeck, M., & De Leo, D, 2013, Suicidal ideation in family carers of people with dementia: a pilot study', *International journal of geriatric psychiatry*, 28(11), 1182-1188.

O'Dwyer, S. T., Moyle, W., Pachana, N. A., Sung, B., & Barrett, S, 2014, 'Feeling that life is not worth living (death thoughts) among middle-aged', Australian women providing unpaid care. *Maturitas*, 77(4), 375-379.

Productivity Commission, 'National Disability Insurance Scheme (NDIS) Costs', 2017, p. 4.

Robinson E., Rodgers B., & Butterworth P., 2008 'Family relationships and mental illness - Impacts and service responses' in Australian Family Relationships Clearinghouse – AFRC Issues, Number 4, 2008.

Schumacher, K., Beck, C. A., & Marren, J. M, 2006, FAMILY CAREGIVERS: caring for older adults, working with their families. *AJN The American Journal of Nursing*, 106(8), 40-49.

Victorian Auditor-General's Office, *Access to Mental Health Services* <https://www.audit.vic.gov.au/report/access-mental-health-services?section=33104--audit-overview#chapter-4>, March 2019.

Victorian Council of Social Services, 'Ensure community mental health services can continue supporting people as the NDIS is rolled out', <https://vcoss.org.au/analysis/ensure-community-mental-health-services-can-continue-supporting-people-as-the-ndis-is-rolled-out>, 2015, accessed 18.03.2019.

Watts, J. H., & Cavaye, J. (2016). Being a Former Carer: Impacts on Health and Well-Being. *Illness, Crisis & Loss*, 1054137316679992.