

1 September 2022

Carer Leave Inquiry
Productivity Commission
Locked Bag 2, Collins St East
Melbourne Vic 8003

Uploaded to: <https://www.pc.gov.au/inquiries/current/carers-leave#issues>

Dear Sir/Madam

Re: Productivity Commission Inquiry - Examination of the potential economic and social costs and benefits of providing an extended unpaid leave entitlement to informal carers of older Australians under the National Employment Standards

The Australian Psychological Society (APS) welcomes the Productivity Commission's inquiry into the economic and social impacts of extended unpaid leave from work for informal (unpaid) carers to take care of older people who are frail and living at home.

The APS works to improve the lives of Australians through psychology. As with all our work at the APS, we also consider issues in light of the global Sustainable Development Goals (SDGs)¹. Of relevance to this inquiry is *SDG 3 Good Health and Wellbeing* which aims to "ensure healthy lives and promote well-being for all at all ages" and includes targets for promoting mental health. The contribution of informal carers is economically and socially significant for many nations, including Australia. Good carer health and wellbeing is the social capital that is essential for the viability of the Australian and global care economy.

We understand that the current inquiry is predominantly focused on extended unpaid leave entitlements for informal carers of older adults in the community in response to the Royal Commission into Aged Care Quality and Safety Recommendation 43 which states that "the Australian Government should examine the potential impact of amending the National Employment Standards under Part 2-2 of the Fair Work Act 2009 (Cth) to provide for an additional entitlement to unpaid carer's leave"².

Inquiry into this matter must, however, be informed by the broader context of the Australian care economy, both formal and informal, and across the aged care, disability and social support system to avoid siloed and ineffective social and economic policy. Thus, we highly commend the Productivity Commission for extending the scope of the inquiry to also consider the impacts of extending unpaid leave entitlements for carers other than carers of older people and alternative policies to support informal carers.

Informal caring and economic impacts

In Australia, there are more than 2.5 million Australians (i.e., 10%) who are informal carers³. As noted in this inquiry issues paper, informal carers who support older people are a critical part of Australia's aged care system, reducing the need for, and costs associated with, formal (paid) care⁴. This also applies to informal care provided to people with disability, and physical and mental ill-health.

The estimated replacement cost for the 2.2 billion hours of unpaid care in Australia in 2020 is \$78 billion, an increase of 29% since 2015⁵. Care for people with a profound disability (across the lifespan, including aged care) accounted for \$51.6 billion of the total replacement value, while care for people with severe disability and moderate/mild disability accounted for \$23.1 billion and \$2.6 billion respectively⁵. Over 350,000 Australian informal mental health carers provided 186 million hours of support in 2018 with a replacement cost of \$13.2 billion^{6,7}. With the ageing population, the demand for informal care among those of all ages living in the community with high levels of care need will increase by 23% while the supply of informal carers will grow by only 16%⁵.

Informal caring also has a significant impact on the labour force participation and financial wellbeing of informal carers. Consider the following:

- Carers are less likely to be employed with 59% of primary carers in the labour force and 77% of non-primary informal carers, compared to 82% for non-carers^{8,9}.
- Carers are more likely to earn less compared to the broader population with a median gross income per week of \$525 for primary informal carers and \$729 for non-primary informal carers, compared to \$863 for non-carers⁹.
- Government pensions or allowances are more likely to be the main source of income for informal carers with 46% of primary carers and 26.5% for non-primary informal carers relying on government income support, compared to 18% for non-carers.
- The opportunity costs due to partially or fully withdrawing from the labour force to provide care is valued at an additional \$15.2 billion in 2020⁵.
- During COVID-19, 1 in 4 (25%) of informal carers had difficulty providing care or assistance because of restrictions put in place with 22% changing their working arrangements¹⁰.

Extended leave provisions are a measure that may improve the workforce participation of some informal carers. However, this may be less likely to assist carers in some situations, for example:

- Extended unpaid leave provisions may enable a carer to become eligible for government support payments yet result in considerably less income and financial wellbeing compared to their employment income.
- Extended periods of leave may be unsuitable for carers of people with episodic care needs or those with relapsing and remitting physical and mental ill-health.
- Work and career is often an important aspect of our lives and for some carers offers them a form of respite and social connection.

In these situations and others, highly flexible working conditions rather than extended unpaid leave periods may better assist carers to provide care and reduce impacts on their income and financial wellbeing.

Informal carer health and wellbeing

Caring for an older person, a person with a physical or mental ill-health or person with a disability can extend for many years or decades⁹. Caring can be experienced as rewarding with a recent Australian survey finding that half of carers (54%) found being a carer satisfying⁸. Yet, caring can also be stressful with 55% of carers reporting low wellbeing compared to 20% of the broader population, or in other words carers are 2.5 times more likely to experience poorer wellbeing⁸. The prevalence of depression and anxiety is higher for carers when compared with matched non-carers¹¹. Physical health can be affected as well, with carers found to be at risk for a variety of stress-related diseases and some reports of higher mortality levels¹². Carers are also at a higher risk of experiencing social isolation, loneliness and stigma¹³⁻¹⁶. Carers of older people with dementia experience higher distress than for carers of older people with physical impairments and intact cognition^{11,17}.

Extended leave provisions may enable carers to better manage the role and challenges that informal caring may bring. However, a single strategy policy lever is unlikely to address the diversity of informal carers needs and the range of unmet support needs carers have identified.

In a recent Australian carers survey, most people reported experiencing many challenges related to their informal carer role: 67% feared for the future of the people they cared for; 64% did not usually have time for themselves, over 40% experienced negative health impacts and relationships, and only 19% of carers were able to easily organise someone to help them in their carer role if they are unwell or need a break⁸. Informal carers also report low levels of formal support. For example, only 24% of primary mental health carers received government income support and 34% received formal service assistance in their caring role¹⁸.

49% wanted more support while 35% did not know what services were available to them¹⁸. Respite care can sustain the informal carer in their responsibilities and support the caring relationship; however there are barriers to accessing services such as cost, availability or lack of knowledge about availability³.

Psychologists are highly skilled mental health professionals that have an important role in helping to support carers over the course of their caring role using evidence-based approaches¹¹. Psychoeducational skill-building interventions and psychotherapy drawing on supportive counselling and cognitive behaviour therapy (CBT) principles can assist carers to manage their own distress and better understand and manage behaviour and environmental stressors for the person they care for^{19,20}.

A 2021 survey of over 500 consumers and carers by Lived Experience Australia (LEA)²¹ found that an overwhelming majority place high value in psychological services and support, with 90% of respondents recommending seeing a psychologist to a friend or family member. The LEA survey results highlight, however, significant unmet need and barriers for people, including carers, seeking psychological support. Only around 60% of consumers and carers were able to see a psychologist within 3-months of referral. The LEA survey results indicated that while Medicare subsidies are helping people to access psychological support, gap fees can prevent some people from accessing help. Over half of consumers and carers surveyed by LEA reported paying a gap fee ranging from \$51 to \$200 with an average gap fee of approximately \$170.

To ensure people get the care they need, when they need it, LEA identified consumers and carers need shorter wait times, more affordable psychological care and more availability of psychologists including those with specific skills in working with diverse groups and trauma.

Summary and recommendations

Informal carers provide substantial support to older people, people with a disability and people with physical and mental ill-health that would otherwise cost the Government billions of dollars for replacement paid care. Yet, there are high levels of unmet support needs for informal carers. An integrated and streamlined social and economic policy approach, that incorporates extended unpaid leave provisions plus a suite of other respite, training and evidenced-based psychological support is needed to support all Australian informal carers and ensure a viable care sector.

The APS:

- Supports extended unpaid carer leave provisions under NES for informal carers who support older people.
- Strongly recommends that improved provisions for hyper flexible working arrangements, in addition to extended leave provisions, are incorporated under the NES to better accommodate the diversity of carer needs. Access to extended leave and other provisions must be easy and streamlined for employees and employers to implement.
- Strongly recommends that any NES changes that support carers of older people be extended to other carers, for example carers of people with a disability, and people experiencing physical and mental ill-health.
- Strongly recommends that the government urgently fund more psychology training places to ensure carers can gain access to psychological support where and when they need it.

If any further information is required from the APS, we would be happy to be contacted through the national office on (03) 8662 3300 or by email at z.burgess@psychology.org.au

Kind regards

Dr Zena Burgess, FAPS FAICD
Chief Executive Officer

The APS would like to acknowledge and sincerely thank the members who so kindly contributed their time, knowledge, experience and evidence-based research to this submission.

References

1. United Nations Department of Economic and Social Affairs. (2022). *Sustainable Development*. <https://sdgs.un.org/>
2. Royal Commission into Aged Care Quality and Safety. (2021). *Royal Commission into Aged Care Quality and Safety Final Report—List of recommendations*. <https://agedcare.royalcommission.gov.au/sites/default/files/2021-03/final-report-recommendations.pdf>
3. Australian Institute of Health and Welfare. (2021, September 16). *Informal carers snapshot*. Australian Institute of Health and Welfare. <https://www.aihw.gov.au/reports/australias-welfare/informal-carers>
4. Productivity Commission. (2022). *Carer leave: Issues paper*. Australian Government.
5. Deloitte Access Economics. (2020). *The value of informal care in 2020. A Report for Carers Australia*. <https://www2.deloitte.com/content/dam/Deloitte/au/Documents/Economics/deloitte-au-dae-value-of-informal-care-310820.pdf>
6. Diminic, S., Hielscher, E., Lee, Y. Y., Harris, M., Schess, J., Kealton, J., & Whiteford, H. (2017). The economic value of informal mental health caring in Australia. *MIND Australia*. https://www.mindaustralia.org.au/sites/default/files/publications/The_economic_value_of_informal_mental_health_caring_in_Australia_summary_report.pdf
7. Diminic, S., Lee, Y. Y., Hielscher, E., Harris, M. G., Kealton, J., & Whiteford, H. A. (2021). Quantifying the size of the informal care sector for Australian adults with mental illness: Caring hours and replacement cost. *Social Psychiatry and Psychiatric Epidemiology*, 56(3), 387–400.
8. Centre for Change Governance and NATSEM, University of Canberra. (2021). *Caring for others and yourself: The 2021 Carer Wellbeing Survey*. https://www.carersaustralia.com.au/wp-content/uploads/2021/10/211011_Carer-Wellbeing-Survey_Final.pdf
9. Furnival, A., & Cullen, D. (2022). *Caring Costs Us: The economic impact on lifetime income and retirement savings of informal carers. A report for Carers Australia*. Carers Australia. <https://www.carersaustralia.com.au/wp-content/uploads/2022/04/Final-Economic-impact-income-and-retirement-Evaluate-Report-March-2022.pdf>
10. Australian Bureau of Statistics. (2022, July). *Household impacts of COVID-19 survey*. <https://www.abs.gov.au/statistics/people/people-and-communities/household-impacts-covid-19-survey/latest-release>
11. Knight, B. G. (2016). Family carers of frail older adults: An often forgotten potential client group. *InPsych*, 38(6). <https://psychology.org.au/inpsych/2016/december/knight>
12. Roth, D. L., Fredman, L., & Haley, W. E. (2015). Informal caregiving and its impact on health: A reappraisal from population-based studies. *The Gerontologist*, 55(2), 309–319. <https://doi.org/10.1093/geront/gnu177>
13. Lim, M. H. (2020). *Loneliness in the time of COVID-19. June/July(3)*. <https://psychology.org.au/for-members/publications/inpsych/2020/June-July-Issue-3/Loneliness-in-the-time-of-COVID-1>
14. Victor, C. R., Rippon, I., Quinn, C., Nelis, S. M., Martyr, A., Hart, N., Lamont, R., & Clare, L. (2021). The prevalence and predictors of loneliness in caregivers of people with dementia: Findings from the IDEAL programme. *Aging & Mental Health*, 25(7), 1232–1238. <https://doi.org/10.1080/13607863.2020.1753014>
15. Consonni, M., Telesca, A., Dalla Bella, E., Bersano, E., & Lauria, G. (2021). Amyotrophic lateral sclerosis patients' and caregivers' distress and loneliness during COVID-19 lockdown. *Journal of Neurology*, 268(2), 420–423. <https://doi.org/10.1007/s00415-020-10080-6>
16. Greenwood, N., Mezey, G., & Smith, R. (2018). Social exclusion in adult informal carers: A systematic narrative review of the experiences of informal carers of people with dementia and mental illness. *Maturitas*, 112, 39–45.
17. Knight, B. G., & Losada, A. (2011). Family caregiving for cognitively or physically frail older adults: Theory, research, and practice. In *Handbook of the psychology of aging* (pp. 353–365). Elsevier.
18. 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.
19. Coon, D. W., Keaveny, M., Valverde, I. R., Dadvar, S., & Gallagher-Thompson, D. (2012). Evidence-based psychological treatments for distress in family caregivers of older adults. In *Making evidence-based psychological treatments work with older adults* (pp. 225–284). American Psychological Association. <https://psycnet.apa.org/record/2012-02568-007>
20. Corry, M., While, A., Neenan, K., & Smith, V. (2015). A systematic review of systematic reviews on interventions for caregivers of people with chronic conditions. *Journal of Advanced Nursing*, 71(4), 718–734. <https://doi.org/10.1111/jan.12523>
21. Lived Experience Australia. (n.d.). *Consumer & carer experiences of psychological services*. https://www.livedexperienceaustralia.com.au/_files/ugd/07109d_2814e70b9ef94966949a7a283f29ed3f.pdf?index=true

