



# Companies who Care

## A support program to address the information needs of carers

Companies who Care (CwC) is an optional support for staff or clients identified as needing assistance as family carers. It is not a replacement for the psychological support that an employee assist program (EAP) provides. In recent years, research has investigated the role of family carers, in particular what the care journey entails and what supports these carers need.

With an increasingly ageing population globally, family members take on the care role, while at the same time managing paid employment and juggling other roles (Vos et al., 2021). In Australia, older people are living longer, many with chronic health conditions. Government programs support older Australians who generally wish to remain at home independently as they age. The 2017–2018 National Health Survey (NHS) found that 80% of older people have at least one or more health conditions such as cardiovascular disease, cancers, chronic renal disease, arthritis, painful musculoskeletal conditions, and dementia (AIHW, 2023a).



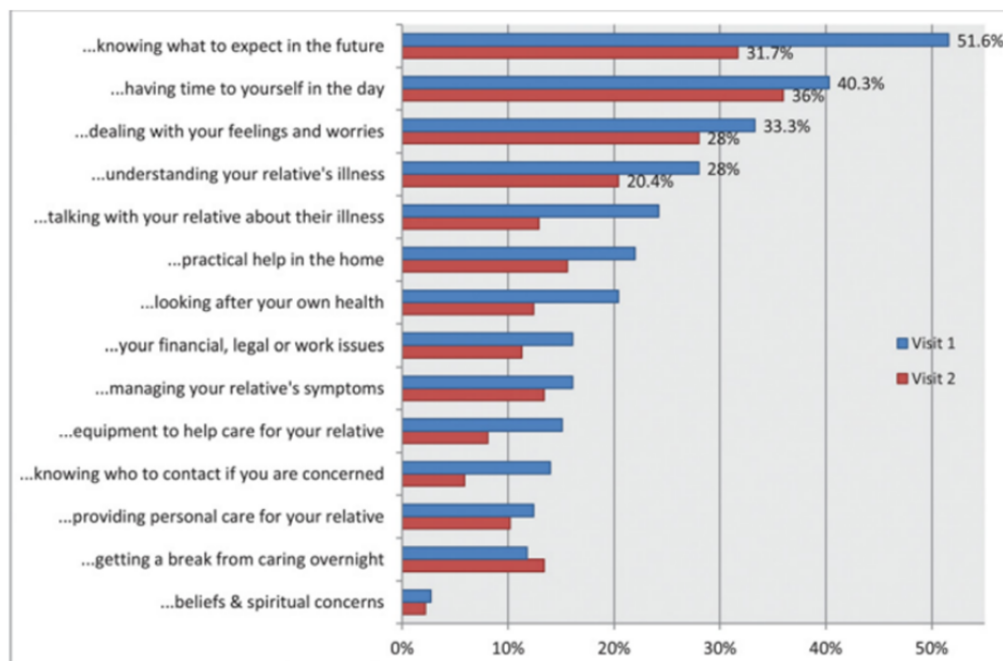
**Companies who Care**



**Palliative Care**  
Western Australia  
*Living, dying & grieving well*

Other concerns related to how to access help and equipment, attending to legal and financial matters, knowing who to contact if concerned and addressing spiritual beliefs. At follow-up, the intervention group (those carers who had their needs addressed) showed significant reduction in carer strain compared with the control group (Aoun et al., 2015). [See Figure 1 on Support needs below]. This local study has been part of a broader international research effort and the findings have been replicated in numerous care situations apart from palliative care settings.

**Figure 1. Percentage of family carers expressing need for support (Aoun et al., 2015, p.11).**



**Fig 3. Percentage of family carers expressing need for more support with each CSNAT domain during first and second visit from nurse.**

doi:10.1371/journal.pone.0123012.g003

Research also shows that carers who have better caregiving trajectories and end-of-life care experiences have improved bereavement outcomes and are less likely to have Prolonged Grief Disorder (PGD) in time. This seems to be associated with preparedness for the death and the caregiving journey. There is consistent evidence to show that those carers who feel both emotionally prepared and practically prepared have less complicated bereavement and/or comorbidities (Caserta et al., 2019).

As increasing numbers of Australians will need care and support, more employees will be juggling carer demands with paid employment. To address this the Australian Government has launched a Carer Inclusive Workplace Initiative to educate employers to support carers in the workplace (Australian Government, Department of the Prime Minister and Cabinet, 2023).

*“Much of my time was spent trying to wrangle supports and appointments while trying to deal with caring for my husband in the face of his terminal illness diagnosis ... three months of stress and trauma trying to get the right care and support services in places instead of worthwhile time together.*

*The process, not his illness, exhausted us both and I believe took him before time.”*

*(Bereaved former carer, MND Carer survey).*

Therefore, the social and physical care needs of this population are increasing with reliance on family or informal care for help (Vos et al., 2021). These demands are generally more than what the norm is for such relationships and most of these carers are not paid for the care they provide. Such support entails help with activities of daily living and physical function, mental health concerns, old age, disability, and end-of-life matters (AIHW, 2023b). According to the Australian Bureau of Statistics (ABS, 2019) in 2018, 11% (2.65 million people) provided this informal care with an estimated 35% aged between 35 and 54 years. Most carers are women (72%). It is expected that these figures are under-reported.

In 2021, an estimated 1.4 million Australians (12% of the employed population) were providing this informal care while working in paid employment in a workplace. The economic fallout for the carers and their families is significant in terms of lost earnings taking leave from paid employment. In 2020, this alone was estimated to be \$15.3 billion (0.8% of the GDP) (Australian Government, Department of the Prime Minister and Cabinet, 2023).

Unsurprisingly a recent annual Carer Wellbeing Survey shows that carers not only have poor economic outcomes, but health and wellbeing outcomes are also worse than people without carer responsibilities. Local Western Australian research by Aoun and colleagues (2015) to respond to carers' support needs in community palliative care found considerable psychological and social impact to carers. Carers are overlooked and unseen, as they navigate the many barriers and challenges to caring across the care trajectory. This study (620 carer participants) identified that the top four support needs of carers were:

- 1) Knowing what to expect in future (52%)
- 2) Having time for oneself during the day (40%)
- 3) Dealing with feelings and worries (33%)
- 4) Having an understanding of the care recipient's illness (28%).

## About PCWA

Palliative Care WA is the peak body for the palliative care sector across the State. Our Vision is that all people with life-limiting illnesses or conditions, and those important to them, are supported to live, die and grieve well.

A member-based, not-for-profit organisation, our Mission is to support and strengthen the collective voice and impact of the palliative care community, including people with a life-limiting illness or condition and those important to them, carers, health care professionals, volunteers, government and other organisations.



CwC is a support program designed to address carer support needs for employees who find themselves thrust into a care role as their relative's health declines. It is designed to target the information needs that carers have on what to expect during the illness trajectory, where to access the practical, emotional, or spiritual support they may need, such as advance care planning or how to access respite care or equipment.

The CwC team comprises well experienced aged care and end-of-life care health professionals representing multidisciplinary designations in palliative care. It is not a counselling program to meet the psychological support needs of the carers, but rather carers would be encouraged to seek psychological services, such as seeking out EAP support in their organisation if they hadn't already done so. If both psychological needs and practical needs are addressed, it is expected that employees caring for a family member or a loved one will be able to minimise the economic, social and health burden of caring and experience better bereavement outcomes.

## References

Aoun, S.M., Grande, G., Howting, D., Deas, K., Toye, C., Troeung, L., Stajduhar, K., & Ewing, G. (2015). The impact of the carer support needs assessment tool (CSNAT) in community palliative care using a stepped wedge cluster trial. *PLOSone*10(4):e0123012  
doi:10.1371/journal.pone.0123012

Australian Bureau of Statistics, (2019). Disability, ageing and carers, Australia: Summary of findings, 2018. ABS, Australian Government.

Australian Government, Department of the Prime Minister and Cabinet, (2023). Support for informal carers. Commonwealth of Australia

Australian Institute of Health and Welfare. (June, 8, 2023). Older Australians. [Informal carers - Australian Institute of Health and Welfare \(aihw.gov.au\)](https://www.aihw.gov.au/older-australians)

Australian Institute of Health and Welfare. (September, 7, 2023). Informal carers. [Older Australians, Health - selected conditions - Australian Institute of Health and Welfare \(aihw.gov.au\)](https://www.aihw.gov.au/older-australians/health-selected-conditions)

Caserta, M., Utz, R., Lund, D., Supiano, K. & Donaldson, G. (2019). Cancer caregivers' preparedness for loss and bereavement outcomes: Do preloss caregiver attributes matter? *Omega - Journal of Death and Dying*, 80(2), 224-244. <https://doi.org/10.1177/0030222817729610>

Velaga, V.C.; Cook, A.; Auret, K.; Jenkins, T.; Thomas, G.; Aoun, S.M. Palliative and End-of-Life Care for People Living with Motor Neurone Disease: Ongoing Challenges and Necessity for Shifting Directions. *Brain Sci.* 2023, 13, 920. <https://doi.org/10.3390/brainsci13060920>

Vos, E. E., de Bruin, S., van der Beek, A.J., & Proper, K.I. (2021). "It's like juggling, constantly trying to keep all balls in the air": A qualitative study of the support needs of working caregivers taking care of older adults. *International Journal of Environmental Research and Public Health*, 18, 5701. <https://doi.org/10.3390/ijerph18115701>