



**LA TROBE**  
UNIVERSITY

Care Economy  
Research Institute

## Special Edition Newsletter

# MILLIONS OF REASONS TO CARE:

National Carers Week

13th to 19th October 2024



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**Director, Care Economy Research Institute**

## Millions of reasons to care: Building a Stronger Future with a National Carers Strategy



Welcome to this special edition of the Care Economy Research Institute (CERI) newsletter, dedicated to celebrating the unsung heroes of our economy—our carers—during this year's National Carers Week.

In Australia, it is estimated that [nearly 3 million informal carers exist](#), with women making up over [70% of primary carers](#). Recognizing and valuing the work of informal carers as essential to our economy is crucial for building a fair Australia and is central to developing a National Carers Strategy. The Institute supports the Australian Government's initiative to engage in consultations and create a comprehensive and progressive strategy.

Finding support as a caregiver can be both time-consuming and frustrating, particularly when navigating multiple systems and complex service requirements, especially in rural areas with inadequate signposting and subpar IT infrastructure. To make matters worse, our care systems frequently function in isolation, making it difficult to effectively navigate them to obtain the care needed for loved ones.

Caring for family and friends is frequently a necessity rather than a choice, reflecting a reality where the formal care workforce cannot keep pace with increasing demand. Additionally, care does not occur in a vacuum; a one-size-fits-all approach to caregiver well-being fails to consider Australia's cultural and linguistic diversity and the community connections—both local and international—that are integral to everyday caregiving networks.

Factors such as low pay, gender stereotypes, the informal nature of the work, and the emotional and physical demands of caregiving all contribute to the devaluation of care as a career and diminish its overall economic significance.

In shaping a National Carers Strategy, we encourage the Australian Government to take bold steps:

- View care as an evolving ecosystem that fosters networks of support for those receiving care.
- Prioritize support for women, enabling them to be both carers and participants in the workforce without negatively impacting their career trajectories or long-term financial security.
- Shift the narrative to emphasize the value of care skills in career choices.
- Cultivate an environment of lifelong learning and support for carers, ensuring their health and well-being while enhancing outcomes for those they care for.

We look forward to working together with you—our members, partners, and other stakeholders—to shift the dial on care work, improving the lives of carers and those they support.



## **Our research and initiatives to support carers**

As public awareness of the challenges faced by various sectors within the care economy increases, the Institute has been actively pursuing several initiatives to highlight opportunities for addressing these critical issues.

Below is an update on several initiatives set to be published or launched in the coming months.

# Understanding the Care Economy: Key Insights and Information

The term "**care economy**" has attracted considerable attention in the past five years, yet many still find its meaning and significance unclear.

Although countries are creating roadmaps for care and organisations are investing in supportive programs, there is still a lack of insights into the global landscape of care work. In particular, the definition and measurement of the economic value of care remain largely unexplored.

Transforming the narrative around the **value of care** starts with increasing public awareness of its importance and meaning.



The Care Economy Research Institute's **scoping review** aims to assess the depth and reach of care economy programs worldwide, examine how care is quantified, identify emerging themes, and highlight current and future research gaps. Our data extraction and analysis are complete with a paper in its final stages before release.

Unsurprisingly, what we are observing is that relevant studies highlight the significant burdens women face, which adversely affect their quality of life. But stay tuned in to learn about the barriers and facilitators to care provision, the critical need for life-long education, training, and support for carers and why few studies address the positive aspects of caregiving.

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## Making Care Data Accessible: our Care Data Portal

We increasingly depend on data to inform decisions and navigate complex issues. However, the **volume of data** related to care is **extensive**; for instance, the Australian Institute of Health and Welfare (AIHW) manages over 150 data collections pertaining to health and aged care.

In newer areas like the care economy, and particularly regarding informal care, finding relevant data can be challenging. It's estimated that nearly 3 million Australians provide informal care, yet their contributions and needs are often **underrepresented in formal datasets**.





CERI's **Care Data Portal**, currently in its proof-of-concept phase, aims to provide a platform that (a) simplifies **access to existing care data** and (b) **identifies gaps** in datasets related to less-explored areas, such as **informal care networks** and **carers**.

Our goal is to create a framework that emphasizes under-researched aspects of the care economy to support future research and policy development.

The initial build phase will be finished by the end of the year, and we will seek to collaborate with researchers and care providers to test its functionality, so stay tuned for updates.

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## COVID-19's Impact on Informal Care in Aged, Disability, Mental Health, and Veteran Sectors: A Systematic Review

Informal caregivers significantly contribute to the global care and support economy, with their value estimated at **0.8% to 4.9% of a country's GDP** annually.

The COVID-19 pandemic led to increased care demands and negatively affected caregiver wellbeing due to changes in formal support services. According to the **2020 ABS Household Impacts of COVID-19 Survey**, one in six Australians provided informal care, with a quarter facing challenges due to pandemic restrictions, nearly a quarter needing to adjust their work arrangements, and 22% reducing their recreational time.



The Institute's **systematic review**, *"The Impact of COVID-19 on Informal Health and Social Care in Aged Care, Disability, Mental Health, and Veteran Sectors: A Systematic Review of Australian Research papers,"* aims to evaluate research on informal care provision in Australia, identifying research priorities and informal care needs, while highlighting promising interventions to support caregivers over the next two decades.

Set to be published soon, stay tuned for insights from this analysis of the informal health and social care workforce in aged care, disability, mental health, and veteran sectors during the pandemic.

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# Assessment of Online Training for Australian Informal Carers and a Narrative Review of eLearning's Impact on Informal Carers and Care Recipients

The shift to virtual training and support has surged since the COVID-19 pandemic, and the development of eLearning programs for informal carers is no exception.

While the effectiveness of this online approach is widely debated, in-person options are scarce for caregivers who often work in isolated settings or rural areas



To explore what an effective training program might entail, the Care Economy Research Institute commissioned a study to assess the availability of **freely accessible online training programs for informal carers** in Australia.

Additionally, the study included a review of how often eLearning programs led to positive outcomes for care recipients, as well as beneficial support for carers' well-being and skills.

The findings are in and will soon be published, outlining the necessary foundations for creating a comprehensive online training program for informal caregivers, identifying currently under-resourced areas, and suggesting effective ways to reach the target audience of informal carers.



## Caring for loved ones at the end of life can be a lonely experience.

Research from La Trobe's HELP team found that many carers hesitate to accept help from friends and family, often instinctively declining support. Common reasons for this include a desire to avoid being a burden, viewing dying as a private matter, and perceiving a need for help as a sign of weakness.



# The Healthy End of Life Program (HELP)


The HELP framework model takes a **public health approach** to palliative care, redefining it as a shared responsibility. It empowers individuals and communities to collaboratively develop pathways for community- and home-based end-of-life care. By addressing social norms around offering and accepting help, HELP encourages community support during difficult times. This not only benefits those receiving assistance but also helps givers engage with their own vulnerabilities.

Ultimately, HELP promotes end-of-life care as a **collective endeavour**, advocating for its integration into community networks and viewing gaps as opportunities for new initiatives.

With funding from the Wicking Trust and the Victorian Department of Health, and in collaboration with Palliative Care Australia, the HELP model has been transformed into the HELP App.

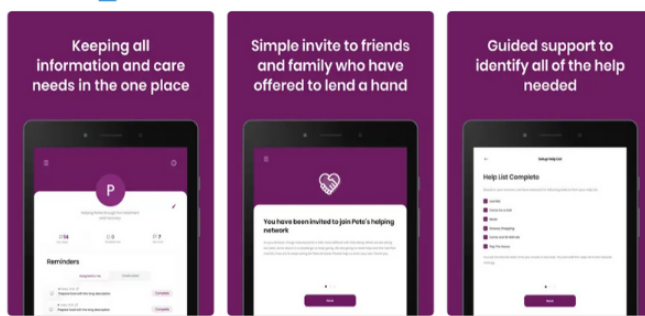
This initiative involves industry partners across Australia, both within and outside the healthcare system, to facilitate referrals for patients, clients, caregivers, and families, enabling them to leverage their social support systems via the HELP App; connecting formal care services with informal community-based care networks.



HELP App   
Healthy End of Life Planning  
The Gather Group Co.  
Designed for iPad  
★★★★★ 4.3 + 0 Ratings  
Free

## The HELP app: Assisting You in Planning, Sharing, and Connecting at the End of Life

Screenshots [iPad](#) [iPhone](#)



The HELP App allows ‘coordinators’—typically family members, caregivers, or individuals receiving end-of-life care—to establish digital networks and request specific assistance by creating tasks that can be managed within the network.

Additionally, it offers tips and resources to encourage and support effective end-of-life planning for optimal benefits.

### Meet a member of the HELP team



**Andrea Grindrod** is the **Director of La Trobe’s Public Health Palliative Care Program** and leads the **‘Healthy End of Life Program’**.

Andrea is focused on creating innovative projects that bridge the gap between practice and research, positioning herself as a unique intersectoral knowledge broker who influences systems, policy, and practice changes.

Over the course of developing the HELP program, Andrea Grindrod has become a **lived experience researcher**, caring for her husband who has stage four terminal cancer. Through a film created at their home, Andrea is using their own experience as a way of promoting the need for people to **offer, ask for and accept help**.

Read Andrea’s insights on her research and what she has discovered about caregivers and end-of-life care.



Q: Andrea, what is one new project you are currently working on?

"I'm currently working on implementing the National Palliative Care Social Prescribing Service Model, recently incorporated into the 2024 National Palliative Care Standards, in collaboration with the Palliative Care Australia.

The model aims to enhance palliative care service provision for clients and families by connecting formal care service delivery with informal community networks of care, unlocking the full potential of a holistic and integrated end-of-life care system."

Q: In your opinion, what is the biggest challenge facing the care economy in Australia?

"One of the most pressing challenges facing the care economy in Australia is caregiver burden. Formal care services are not designed to meet the social and practical elements of everyday community life, leaving primary caregivers responsible for managing holistic care needs. Primary carers are at risk of poor physical, mental and social wellbeing, often compounded by multiple responsibility conflict, lack of respite opportunities, limited social activities and numerous caring roles.

The trajectory of caregiver burden can be even more pronounced for those caring for an individual with terminal illness. While informal caregivers make a substantial contribution to the care economy in end-of-life care, a lack of comprehensive community-based data on how Australians mobilise and support one another at the end of life makes it difficult to measure the full scope of the policy, service delivery and resourcing implications to adequately understand and strategically invest in supporting these carers."

Q: What's the most surprising finding or innovation related to your research you think most people would be surprised to hear about?

"My earlier research showed that despite having rich social networks, many caregivers feel isolated at a time when they need support the most. Carers often don't ask for or receive the emotional or practical help they need, as societal stigma and discomfort with death prevents open conversations and engagement.

Encouragingly, the current community-based data generated by the HELP App is showing signs of a shift. When caregivers are supported to draw upon and utilise their informal care networks, we increasingly see active networks fostering a culture of shared responsibility and open engagement. This data suggests that with the right tools and platforms, we can overcome societal barriers and create supportive environments where caregivers can navigate the complexities of end-of-life care collaboratively, rather than in isolation."



Q: What is one publication or article that you would recommend to anyone wanting to understand more about your research area or broader issues facing the care economy?

"I would suggest reading my paper "[Choice depends on options: A public health framework incorporating the social determinants of dying to create options at end of life](#)", which is published in Progress in Palliative Care.

This paper offers a unique perspective on how public health approaches can be integrated into palliative care strategies to create more meaningful choices for individuals and their families during the end-of-life phase, acknowledging the implication of structural vulnerability in end-of-life choice. It includes an asset-based national public health palliative care framework to build capacity and leadership by leveraging the existing strengths, resources and networks of sectors and communities, offering a strategy to support people at the end of life to remain connected to people, places and possessions that are important to them."



# GreenConnect

## Dementia Respite

### GreenConnect: a novel approach to dementia respite

The number of Australians with dementia is expected to double over the next 25 years with over [1.6 million people currently caring for people living with dementia](#). Dementia is the second leading cause of death amongst Australians and the leading cause of death for Australian women.

Dementia remains a challenging and often misunderstood disease.

**Hear more about this [transformative pilot project](#) from carers and people living with dementia.**

La Trobe University is collaborating with partners in the Loddon-Mallee region to assess the impact of an innovative program that utilizes nature-based activities to support individuals with dementia, transforming our approach to care and support.





## Insights from Institute Members: Exploring Caregiving and Caregivers

Interested in learning more about what our Institute researchers have to say regarding caregivers and caring responsibilities? Explore any of these featured papers:

- Sharafizad, F., Franken, E., Jogulu, U., & Teo, S. (2024). "Being a carer, you just get forgotten!": exploring the experiences and opportunities of informal primary carers in Australia. *International Journal of Care and Caring*, 8(3), 510-526.  
<https://doi.org/10.1332/239788223X16789866214981>
- Petersen, M., Winterton, R., Warburton, J., & Wilson, J. (2024). Negotiating the care convoys for a diverse group of older Australians living in rural communities: a large qualitative study. *Ageing and Society*, 44(7), 1494–1514.  
<https://doi.org/10.1017/S0144686X22000125>
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- Jiang, H., Koen, S., Anderson-Luxford, D., Willoughby, B., Ferrier, J. A., Amany, T., Room, R., Laslett, A.M. (2024) The burden of alcohol-related caring for others in Australia in the 2021 pandemic period. *Journal of Studies on Alcohol and Drugs*, 0.  
<https://www.jsad.com/doi/abs/10.15288/jsad.23-00261>
- Cameron, N., Rayner, J.-A., Fetherstonhaugh, D. and McAuliffe, L. (2024) What is Needed to Provide High-Quality Cultural and Spiritual Care in Long-Term Care Homes? *Journal of Long Term Care*, 0, p. 371–382. <https://doi.org/10.31389/jltc.285>.
- Cooper, K., Sadowski, C., & Townsend, R. (2024). Being a parent, but not: A grounded theory of home-based care. *Family Relations.*, 73(3), 1880–1898.  
<https://doi.org/10.1111/fare.12969>
- Henshall, B. I., Grimes, H. A., Davis, J., & East, C. E. (2024). What is 'physiological birth'? A scoping review of the perspectives of women and care providers. *Midwifery*, 132, 103964.  
<https://doi.org/https://doi.org/10.1016/j.midw.2024.103964>

## Voices of Care: Podcasts Sharing Stories of Caregiving

Storytelling serves as a powerful catalyst for change as we listen to the experiences of carers and narratives surrounding care.

- [The secret life of Carers](#) by [Carers Australia](#) - Personal stories reflecting on life as a carer in Australia, available on [Apple Podcasts](#), [Spotify](#), [Amazon Music](#), [Google Podcasts](#).
- [Jia Tolentino reviews "Essential Labor: Mothering as Social Change" by Angela Garbes](#), who examines how care work "came to be seen as low wage labor, rather than highly skilled work that is essential, creative, and influential."
- [The Care Mosaic Podcast](#) - A seven-episode podcast series showcasing the different experiences of carers across Victoria, including their backgrounds, ideas and aspirations, from [Merri Health's](#) Carer's Gateway Team. Available on [Spotify](#), [Apple Podcasts](#).

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