

Measuring unpaid care in the Labour Account

February 2025

Dementia Australia

Dementia Australia is the peak dementia advocacy organisation in Australia. We support and empower the estimated 433,300 Australians living with dementia and estimated 1.7 million people involved in their care. Dementia is the second leading cause of death in Australia, and the leading cause of death for women, yet it remains one of the most challenging and misunderstood conditions. Founded by carers more than 35 years ago, our organisation engages with people with dementia, their families and carers in our activities, planning, policy and decision-making, ensuring we capture the diversity of the lived experience of dementia across Australia. Our advocacy amplifies the voices of people living with dementia by sharing their stories and helping inform and inspire others. As the trusted source of information, education and support services, we advocate for positive change for people living with dementia, their families and carers, and support vital research across a range of dementia-related fields.

Dementia in Australia

Dementia is the term used to describe the symptoms of a large group of neurocognitive disorders which cause a progressive decline in a person's functioning. It is one of the largest health and social challenges facing Australia and the world. In 2025 there are an estimated 433,300 people living with all forms of dementia in Australia. This figure is projected to increase to an estimated 812,500.¹ An estimated 1.7 million people in Australia are involved in the care of someone living with dementia.²

Introduction

For most people living with dementia, informal carers are an integral part of their lives and are fundamental to their care and capacity to remain safe and supported in their own home or in residential aged care. Carers of people with dementia are often a spouse or child and typically they provide wide-ranging supports including assisting with activities of daily living, personal care and responding to changed behaviours. They are often involved in making decisions about treatment and care options, service provision and financial arrangements. Carers of

¹ Dementia Australia (2023) Dementia Prevalence Data 2024-2054, commissioned research undertaken by the Australian Institute of Health and Welfare

² Based on Dementia Australia's analysis of the following publications - National Dementia Action Plan; Australian Institute of Health and Welfare (2024) 2023 Aged Care Provider Workforce Survey: Summary report, AIHW, Australian Government

people living with dementia play a critical role but face their own challenges which include balancing work and care, accessing and navigating the aged services and support system, financial constraints due to taking on the carer role, impacts on their own physical and mental health and a range of other issues. Caring is often a full-time role and one that substantially contributes to the quality of life of those living with dementia.

This submission will specifically address the section on measuring unpaid care for adults, with a particular emphasis on the experiences of those caring for people living with dementia.

Recommendations

Some considerations for the ABS to consider in developing initial estimates of unpaid adult care in the Labour Account:

Underreporting and non-identification as carers

Some carers of people living with dementia may not identify themselves as carers, particularly in familial relationships such as spouses or adult children, where they perceive their role as fulfilling family responsibilities. This can lead to underreporting of unpaid care. Additionally, carers from diverse backgrounds, including culturally and linguistically diverse (CALD) communities, Aboriginal and Torres Strait Islander (ATSI) communities, and LGBTQIA+ communities, may face additional barriers in recognising and reporting their caring roles due to cultural expectations, stigma, or language barriers.

Recommendation: The ABS should develop an inclusive methodology for capturing all unpaid carers, ensuring representation from diverse groups. This could involve using culturally appropriate terminology, broadening definitions of care, and engaging with representative organisations to improve identification and reporting of unpaid care across different communities.

Recognition of informal care in aged care settings

Informal care does not necessarily end when a person moves into residential aged care. Many carers, particularly family members, continue to provide significant support, including:

- Assisting with daily activities such as feeding, dressing, and personal care.
- Providing emotional support and companionship.
- Advocating for the person's needs and liaising with facility staff.

Current data collection methods may fail to account for informal care within residential aged care settings, leading to an underestimation of the true extent of unpaid care.

Recommendation: The ABS should explicitly include informal care provided within residential aged care facilities in its definitions and measurement frameworks as well as surveys and data collection tools. This should include specific questions about ongoing support provided by informal carers in residential aged care settings.

Capturing indirect care

Unpaid care extends beyond direct physical support and includes significant indirect activities such as managing finances, coordinating medical appointments, or providing emotional

support over the phone. These activities may be overlooked in traditional measures of care, yet they represent a significant proportion of caring responsibilities.

Recommendation: The ABS should expand its framework to explicitly capture indirect caring responsibilities.

Short-term and ongoing care

Caring will vary in intensity, whether it is stepping in short-term, or caring that increases after hospitalisation or emergencies, and care can fluctuate depending on the stage of dementia or symptoms.

Recommendation: Include data collection that can indicate fluctuating levels in caring intensity.

Consulting with carers of people living with dementia

To ensure that estimates of unpaid care accurately reflect lived experiences, the ABS should engage directly with carers of people living with dementia. Dementia Australia has developed a comprehensive guide to meaningful engagement with people living with dementia, families and carers called **Half the Story**. Meaningful engagement means seeking out, affirming, and ratifying the voices of people living with dementia, families, and carers to understand the full story.

Conclusion

We thank the Australian Bureau of Statistics for considering this submission and would welcome any further opportunities for consultation.