

Submission to the Productivity Commission's consultation on Carer's Leave

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Background

The Continenence Foundation of Australia welcomes the Productivity Commission's consultation on the provision of Carer Leave, and the economic and social impacts of allowing informal carers to take extended unpaid leave from their work to care for older people who are frail and living at home.

The Foundation supports the introduction of unpaid leave for carers as an important step in recognising the important role of carers and the unfair burden caring places on many people who take on this role. We believe the role of informal carers in supporting older people to continue living in the community cannot be underestimated, and provisions that enable them to undertake this role are most welcome. We know that caring for people with incontinence has an impact on carers and is often an overlooked aspect of their caring role.

- The Australian Institute of Health and Welfare found three in four carers spent 40 hours or more per week caring for someone with incontinence.¹
- Primary carers who assisted with managing incontinence reported feeling weary and lacking energy or being worried or depressed at significantly higher rates compared with carers who did not usually assist with managing incontinence.²
- It is likely these factors impact workforce participation with primary carers aged 15 to 64 who help manage incontinence having lower levels of employment than carers who did not (44.3% vs 55.4%). It also translates to lower levels of full-time employment where only 15.2% of people who care for a person with incontinence are in full time employment compared to 26.7% of carers who did not.¹
- In the Foundation's 2022 National Consumer Survey³ 49% of people caring for someone with incontinence report that caring for them has some financial impact, with 7% reporting they are struggling financially; 72% report that it severely impact their life, with 51% reporting it affects their mental health and wellbeing.

Preventing older Australians from entering residential aged care for as long as possible, by supporting informal carers to extend or expand their role as a carer, would potentially have significant benefit for the older person experiencing incontinence:

- Incontinence is one of the top three critical factors identified for older Australians needing to transition from home-based aged care to residential aged care facilities. Faecal incontinence increases the risk of being recommended for residential care by 86%, and urinary incontinence by 39% (compared to 83% for a diagnosis of dementia).⁴
- Incontinence associated dermatitis is defined as skin inflammation manifested as redness with or without blistering, erosion, or loss of skin barrier function that occurs because of chronically or repeated exposure of the skin to urine or faeces. The prevalence of IAD in nursing homes is between 3.1% and 6.5%.^{5,6}

While the current focus on leave entitlements for carers of older Australians is welcome, the Foundation suggests that this consideration should be extended to carers of people with disability under the age of 65 years.

We would like to also bring to the attention of the Productivity Commission the following matters that impact on the quality of life for older Australians and their carers who are living with incontinence:

- Currently one in four people in our communities are affected by incontinence. An estimated 316,500 Australians live with both incontinence and disability.¹
- The impacts of incontinence are far reaching and can affect a person's physical, mental and emotional health and wellbeing.
- Incontinence is a highly personal and stigmatised condition which can often be treated, improved or better managed. It can also have profound negative effects on those living with incontinence and their carers, restricting their interactions with family, work and the community. Because of the stigma and shame, many people and their carers keep their condition secret, which adds an extra dimension of suffering and leads to social isolation, higher psychological impact and delayed helpseeking.⁷
- Despite its health, social and economic consequences, incontinence is often considered a normal part of ageing and thus is not well understood or prioritised in care for older Australians, particularly those living in residential aged care facilities.
- An estimated 1.17 million community-dwelling Australians aged 65 years and over were living with incontinence in 2010. In the same year, an estimated 128,473 residents (71%) in aged care facilities had urinary or faecal incontinence or both. The number of residents with these conditions is projected to increase to 253,113 by 2030.³
- The rates of urinary incontinence for older home care consumers (≥65 years) ranges from 28 to 51% and the rate of faecal incontinence for older home care consumers is 14% or one in seven.⁸ The home-care population which lives with incontinence is also at a significantly higher risk of health complications including falls, dementia, impaired function of daily living, cognitive impairment, longer periods of hospitalisation and mortality.⁹⁻¹³
- Currently, continence care and incontinence management are not being managed effectively. Since 2015, complaints regarding continence management in residential aged care to the Aged Care Quality and Safety Commission (and the Aged Care Complaints Commission before that) have ranked in the top 5 most common issues subject to complaint.¹⁴⁻¹⁶

For 30 years, the Foundation has represented the interests of Australians affected by, or at risk of, bladder and bowel control problems and act as an advocate for their interests. The Foundation has also worked with a range of professionals across the health, aged care, disability, community and fitness sectors to implement programs, deliver education and provide advice and resources.

We look forward to working with the Productivity Commission and the Australian Government to ensure people with incontinence and their carers are supported to have a good quality of life and meaningful participation in their community.

Yours faithfully

A handwritten signature in black ink, appearing to read 'Karen Cashell', with a large, stylized initial 'K'.

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