# Continence Health

## Can incontinence be accepted as a long-term health condition?

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## Introduction

The Continence Foundation of Australia (the Foundation) welcomes the opportunity to make the case for Incontinence to be considered as a long-term health condition.

This document gives the Foundation the opportunity to bring to your attention the urgent requirement for robust data collection to adequately fill the information gaps that exist currently in relation to the continence health of Australians and cannot be met through existing administrative data collection means.

The Foundation's experience and expertise as a health peak body will enable us to assist the Government in identifying current data gaps which are impediments to the public and professional awareness of risks to continence health across the life course and the development and delivery of evidence-based, high-quality continence care and incontinence management.

Given the paucity of robust data of the prevalence of incontinence in the Australian population we need to close the damaging gaps in information.  These gaps also contribute to the well documented stigma and silence on this issue and obstructs progress on improving the continence health of the population to be addressed.

## The Continence Foundation of Australia

The Continence Foundation of Australia (the Foundation) is the peak not-for-profit organisation for bladder and bowel health, continence health and support for people with incontinence, their families and carers and the health professionals supporting them. The Foundation has worked with and is led by continence health experts across the medical, nursing, physiotherapy and other allied health sectors. It has also built and is continuing to progress strong consumer leadership within the organisation.

The Foundation works with people of all ages impacted by incontinence and with carers, as well as government and other stakeholders to provide support services, education and information aimed at reducing the stigma and restrictions of incontinence, to compile evidence of best practise in the prevention and management of incontinence and to improve services for people living with incontinence.

## Data and Information Gaps

The paucity of data on incontinence is one of the most significant barriers to the provision of appropriate, adequate and effective services for people living with incontinence and for those at risk of developing incontinence. There is no comprehensive population-based data on prevalence of incontinence in Australia. (Deloitte 2023) or incidence in specific populations. The most comprehensive recent data is provided through the Foundation commissioned Deloitte Access Economic report (2023 which updated a previous report from 2011) and the AIHW analysis from the 2007-2008 and 2011-2012 national health surveys.

The lack of high-quality Australian epidemiological data on either urinary or faecal incontinence in adult women and men severely limits the visibility of this as a health issue. Data on incontinence in children is equally limited.  Very few studies have attempted to measure the prevalence of incontinence across the population of Australia. Much of the existing data is either out of date or not disaggregated by sex. Very little is known about the prevalence and risk factors amongst women and men from Aboriginal and Torres Strait Islander, CALD and LGBTQIA+ communities (AIHW 2013, Deloitte Access Economics, 2023).

## Prevalence of Incontinence

Incontinence affects all age groups. (Hawthorne 2006, Botlero et al 2008, Buckley & Lapitan 2010, Markland et al 2011; AIHW 2-13; Deloitte Access Economics 2023).

See Chart 1 Below

Chart 1: Estimated Prevalence 2023

| | | UI | FI | Total | % of Total |
|---|---|---|---|---|---|
| Prevalence | Male | 1,948,626 | 487,537 | 2,436,164 | 33 |
| | Female | 4,417,715 | 422,876 | 4,840,591 | 67 |
| | Persons | 6,366,341 | 910,413 | 7,276,754 | |

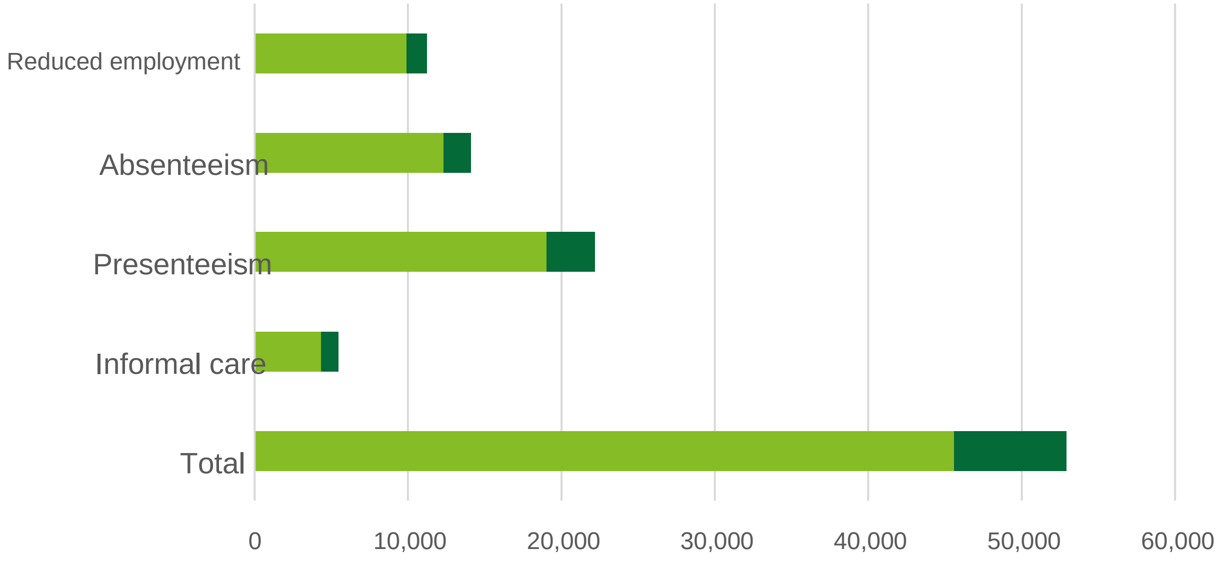
Source: Deloitte Access Economics 2023

These numbers show that the prevalence of incontinence in Australia has increased over the past 10 years. In 2023, 7.3 million Australians aged 15 and over had some measure of incontinence compared to 4.8 million in 2010. This represents a 53% increase since 2010. While the prevalence rate increases with age, a majority (71%) are between 15 and 64.

**Over 7.2 million people in the community live with some degree of incontinence. While prevalence rates are higher in residential aged care, the vast majority of people with incontinence live in the community and are of working age. There are significant productivity costs arising from the burden of incontinence.**

See Chart 2 below:

**Productivity costs due to incontinence by cost component in 2023**



**Source: Deloitte Access Economics, 2023**

Assuming the estimated 2023 prevalence rates hold over the next 10 years to 2032, it is estimated that there will be 8.6 million people (or 34% of the population) with urinary and/or faecal incontinence in 2032. (Deloitte 2023). This clearly demonstrates an urgent need for population level data to both confirm this estimation and to ensure robust future health planning.

## Incontinence in Women

The available evidence suggests that the biggest risk factor for incontinence is being female (Hunskar et al; Sharma 2010). Risk factors for women include:

- Pregnancy and vaginal delivery (Kilic 2016)
- Parity (having had children) is a risk factor for urinary incontinence in young and middle aged women (Wesnes et al 2017)
- Childbirth can cause anatomical or neuromuscular injury and can damage the pelvic floor muscles Vaginal delivery, forceps use and heavy babies are all risk factors (Wesnes et al 2017)
- Urinary incontinence is more frequent in women with urinary tract infections (Govender et al 2019)
- Urinary incontinence sometimes starts at the same time as the menopause (Trutnovsky et al 2014; Aoki et al 2017)
- Hysterectomy is related to stress urinary incontinence, particularly vaginal hysterectomy (Melville et al 2005)

## Incontinence in Female Athletes

A recent systematic review of urinary incontinence during exercise and sports is a concern for young female athletes. This systematic review identified nine studies published between 2002 and 2020. The total sample was 633 female athletes, with an average age of 16.15 years, BMI ranging from 18.9 to 21.7 kg/m$^2$, and 6–19 hrs of training per week. Findings from the review highlight a 48.8% prevalence rate among adolescent female athletes where practitioners of high-impact sports show the highest prevalence rates. (T. Rebullido 2021)

A recent study of female netball players in Ireland identified that urinary incontinence (UI) is prevalent among this cohort of elite female Gaelic sports athletes. Risk factors for UI among the players include parity and greater weekly time spent in sporting activity. Players utilized strategies to manage the symptoms of UI rather than seek help for what is a treatable condition. This study suggests a need for increased awareness and education regarding pelvic floor health and the treatment of UI among these players. 159 players completed an on-line assessment tool.

- Urinary incontinence was reported by 61.6% of respondents.
- 52% experienced stress urinary incontinence.
- Parous players were more likely to experience urinary incontinence
- Jumping and sprinting activities were the most commonly reported triggers

(Culleton-Quinn et al 2024)

## Incontinence in Men

There is a perception that incontinence rarely affects men and when it does it is perceived as a normal consequence of ageing. A recent report commissioned by the Foundation by Deloitte Access Economics estimated that currently 7,276,754 Australians are living with incontinence, 2,436,164 of this total are men. Risk factors for males occur across the life course and include: -

- Constipation
- Medications
- Prostate problems
- After prostate cancer surgery
- After bowel cancer surgery
- After bowel, bladder and prostate radiation treatment
- Obesity
- Chronic conditions (e.g. diabetes, cardiovascular disease)
- Impaired mobility (e.g. stroke, dementia, arthritis)
- Disability

## Incontinence in Children

There is also a paucity of robust data on incontinence in Children aged 5-14 in Australia. According to data collected in the first full year of school by teachers, through the Australian Early Development Census (AEDC), [i] the incidence of children not being fully toilet trained by the time they start school is increasing over time (from 1.96% in 2012 to 2.86% in 2021). However, it is generally accepted that the experiences of children with incontinence are different to those of adults. Diagnosis is often delayed by the perception that daytime wetting, bedwetting and to a lesser extent, soiling, is normal in children. The Foundation and the International Children's Continence Society estimate that 3-12% of children experience day wetting, 1-3% experience soiling and nearly 20% experience bedwetting. However, the prevalence is difficult to determine due to underreporting, inconsistent definitions and regional variations. Treatment for incontinence is also different for children, reflecting age-specific considerations and differences in the causes of incontinence. There is an urgent need to know more about the numbers of children affected by incontinence, the characteristics and the impacts on family members.

## Priority Groups Aboriginal and Torres Strait Islander communities

There is little data to estimate the prevalence of incontinence among Aboriginal and Torres Strait Islander populations. There are some indications in the available literature to indicate that these populations may have a higher rate of urinary incontinence due to higher associated risk factors such as obesity and diabetes.

These factors identify an urgent need for more comprehensive data collection for this population to understand better the prevalence rates and their specific needs.

## Culturally and linguistically diverse communities (CALD)

Despite the fact that large segments of the Australian population are from CALD backgrounds, evidence of the prevalence of incontinence in the various CALD population groups is lacking. Better population data collection in relation to continence health is needed in order to understand the scale of continence health issues in all CALD communities.

## Lesbian, gay, bisexual, transgender, queer, intersex and asexual plus (LGBTQIA+)

It has been reported that LGBTQIA+ people are more likely to avoid seeking healthcare. This may reflect the stigma and discrimination they experience in healthcare settings (Deloitte, 2023).  There is limited evidence on the self-seeking behaviours of LGBTQIA+ people in relation to incontinence.

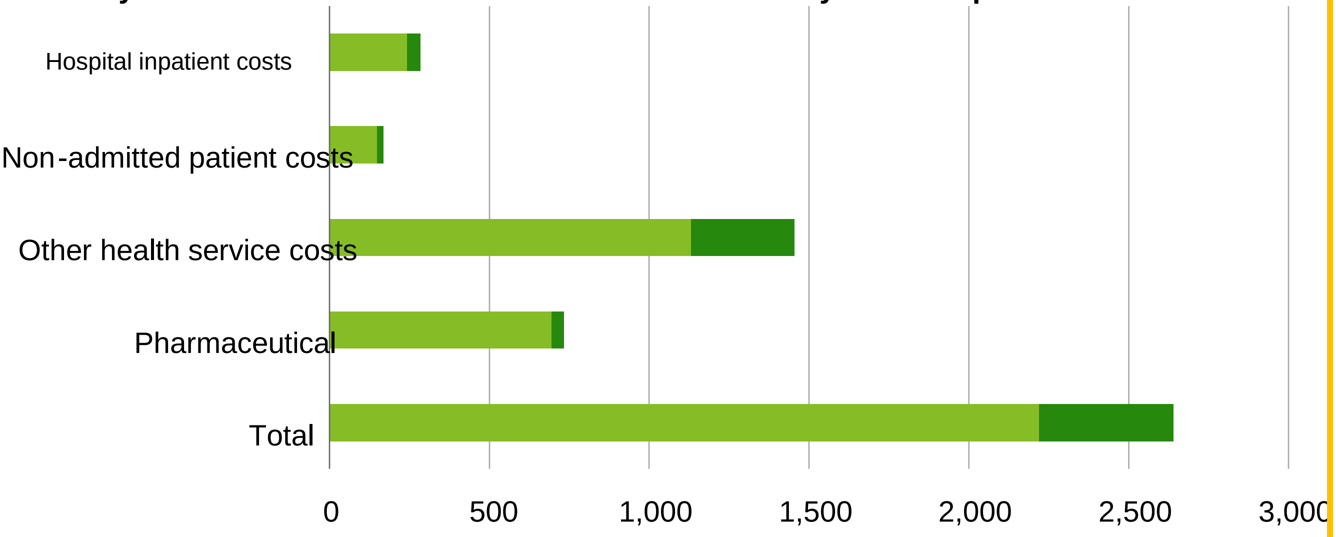
There is limited yet robust evidence of the impacts of hormonal or surgical intervention provided as part of gender-affirming care.  The available evidence suggests that there may be risks to continence health from some procedures.  There is, however, significant international evidence of barriers to informed healthcare for transgender individuals, which will affect their ability to protect their continence health (Safer et al 2016) Van de Grift et al 2017). There is some evidence that access barriers may be greater for female-to-male transgender individuals (Salkas et al 2018).

## Impacts on Adult Mental Health & Wellbeing

Deloitte Access Economics provide figures that suggest that in 2023, 45.3 % of health care costs provided to community dwelling adults living with incontinence was related to consultations with GPs and 20% with mental health professionals. Other health service costs comprised the largest proportion of health system costs, accounting for $1.5 billion (55.0% of the total cost. This included visits to general practice, allied health, and mental health professionals in relation to incontinence.

Chart 3

**Health System Costs attributable to incontinence in 2023 by cost component.**



**Source: Deloitte Access Economics, 2023, based on data from AIHW, NHCDC, PBS, Chemist Warehouse, and Deloitte consumer survey.**

These figures are reflected in the findings of the Foundation’s 2024 Consumer Survey which indicated that there is a substantial impact on the mental health of respondents who live with incontinence.

Chart 4

**Reasons why People Living with Incontinence Report Poor Health**

| **2024 themes**<br>**(n=298)** | | | |
|---|---|---|---|
| Mental health struggles | 6.9% | Heart conditions | 4.8% |
| Multiple painful conditions | 6.6% | High Blood Pressure | 4.8% |
| Chronic back pain | 6.2% | Physical health struggles | 4.8% |
| Arthritis | 5.5% | Type one diabetes | 4.8% |
| Breast cancer | 5.2% | Chronic health conditions | 3.8% |

**Source: Continence Foundation of Australia. National Consumer Survey 2024**

There is growing evidence of the associations between incontinence and psychosocial factors, including depression but, currently, there is no Australian population level data to determine the incidence of comorbid mental health problems associated with the experience of living with incontinence.

## Impact on Carers

There is extensive evidence that caring for a person with incontinence can have significant and negative impacts on carer’s quality of life, through social isolation, financial problems as well as psychological and physical exhaustion. Lack of appropriate support on the general silence regarding the problem it is still considered a taboo by many may aggravate the situation for carers. Conversely there is strong evidence to suggest that with the provision of appropriate support including psychological support carers find it easier and even rewarding to respond to the needs of people living with incontinence. Lack of data about numbers of locations and characteristics of carers of people with incontinence in Australia is a significant hindrance to effective planning of appropriate measures of support.

The Foundation’s Consumer Survey (2024) provide additional insight into the multi factorial, nature of the burden faced by carers.

Table 1

**Impact on Carers**

| | | |
|---|---|---|
| **Carers** | • 30% of Australians currently care for or have cared in the past for someone who has incontinence.<br>• 44% of carers say that caring for someone with incontinence impacts their mental health and well-being and makes them less confident to leave the house.<br>• 40% of carers say that caring for someone with incontinence prevents them from going about their day-to-day activities (compared to 57% in 2022).<br>• 12% of carers indicated it affects their mental health and wellbeing.<br>• Carers are far more likely to have incontinence now (21%) or in the | • Over 29% of survey respondents have cared for or are caring for someone with incontinence. Of these, 49% are male, 51% are female, and 55% are over 40.<br>• Caring for<br>– Parent or parent-in-law 42%<br>– Grandparent 22%<br>– Spouse/partner 18%<br>• Over 77% of the carers discussed their caring experience and about incontinence with someone. Nearly 68% were with a health professional, and 48% were with a |

| | | |
|---|---|---|
| | • past (13%) than those who never had it (4%).<br>• 52% of the care is provided by a spouse or partner.<br>• There is a higher incidence of having incontinence (10%) in carers or past carers of someone with it (16% combined with 7% if never been such a carer).<br>• There is a higher incidence of having had incontinence (29%) in carers or past carers of someone with it (45% combined with 23% if never been a carer).<br>• Those more likely to receive care/support for incontinence (14%) are current or past carers (23%) than others (6%).<br>• Those more likely to receive care/support for incontinence (14%) are current or past carers who tend to have looked after an older generation, a parent/parent-in-law (43%) or grandparent (18%) more than contemporaries like their spouse/partner (20%) or a younger generation like a child or adolescent.<br>Nearly half of carers cited some financial impact (12% significantly impacted). The 2022 survey found that 7% of carers struggled financially, and 42% reported some impact. | GP or family doctor. In contrast, 23% did not discuss it with anyone.<br>• While most of the carers (64%) feel supported to participate in community activities, there is a sizable number of just under 50% who feel less confident leaving home and have reported it affecting their mental health and their relationships with family and friends.<br>• Impact on caring for someone:<br>Feel supported to participate in community activities 64%<br>Less confident to leave home 46%<br>Affects my mental health and wellbeing 51%<br>Prevents going about day-to-day activities 46%<br>Impacts my relationship with family and friends 38% |

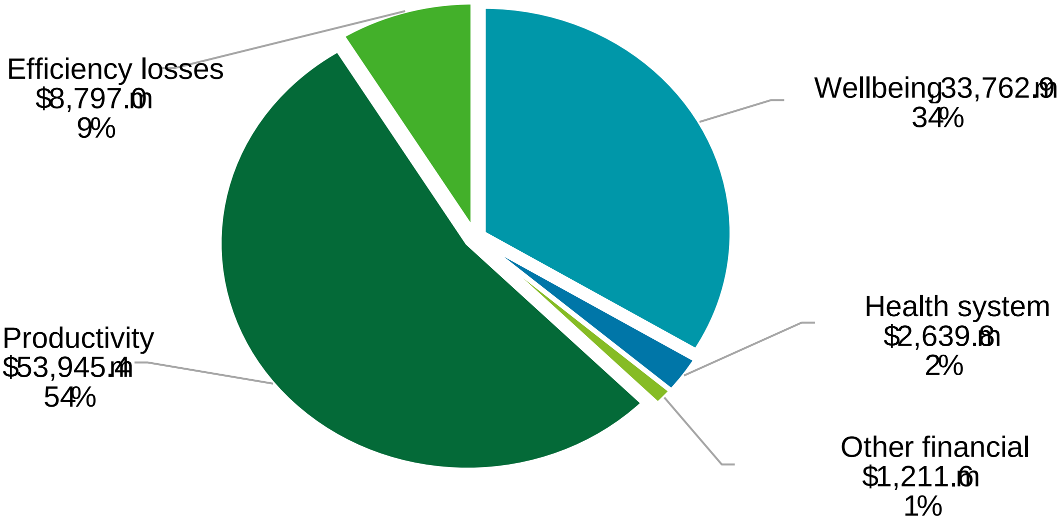
Source: Continence Foundation of Australia. 2023

## Incontinence is costly

Increasing prevalence of incontinence has an impact on costs. In 2023 the total cost of incontinence in Australia was $66.6 billion, with an additional $33.8 billion in lost wellbeing (Deloitte 2023).

The estimated economic cost of incontinence per person experiencing incontinence was $9,152 in 2023. This figure includes both direct and indirect costs arising from poor continence health. These include costs arising from the utilisation of healthcare and other social support systems, the costs of aids and adaptations, impacts on employment and work, and lost wellbeing. These costs are paid by governments and health systems and ultimately by taxpayers and individuals. These figures are not disaggregated by sex. Data compiled by the European Union indicates that the economic burden for females was four times higher than males, and the economic burden increases by 16% when accounting for the informal support provided by caregivers.

These figures also do not include the considerable financial and environmental costs associated with the disposal of continence aids and products,



## Conclusion

Incontinence is embarrassing, highly stigmatised and dramatically increases social isolation. Recent surveys show that more than 70% of people living with incontinence do not seek treatment.

The lack of reliable population-based data on incontinence has significantly impeded the efficient delivery of services to affected communities. Policymakers and healthcare providers struggle to prioritise and deliver without comprehensive and accurate data on the prevalence, types, and severity of incontinence across different demographics. This also impacts the identification of at-risk populations, delays early intervention, and contributes to disparities in care, ultimately limiting the overall impact of treatment and prevention strategies. Addressing this data gap would enable more targeted, equitable, and cost-effective care for individuals living with incontinence.

In addition, there is an urgent need to know more about the characteristics and needs of carers of people with incontinence to enable the targeted delivery of evidence based psychosocial support. This would prevent the costs associated with health and residential care resources and improve well-being for both individuals living with incontinence and carers.

As a prevalent and pervasive stigmatised health condition that has substantial impact on the health and wellbeing of individuals and contributes significantly to the burden of demand for health care of management of complex care needs, chronic health conditions and for the ageing population, incontinence has been neglected in health policy and persistently underfunded when compared to need and cost impacts.

Despite its significant impact on individuals and the sizable costs to the economy, there continues to be insufficient attention to robust population data collection.

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