

# The Need for Recognition of Incontinence as a Long-Term Health Condition

## Position Statement from Continence Health Australia

November 2025

### Continence Health Australia

Continence Health Australia - CHA (formally Continence Foundation of Australia - CFA) is the lead body for continence health in Australia. CHA has worked with and is led by continence health experts across the medical, nursing, physiotherapy and other allied health sectors.

CHA has also built and is continuing to progress strong consumer leadership within the organisation.

CHA 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.

### Purpose

This position statement has been prepared by CHA. The paper discusses the evidence that incontinence is a highly prevalent, debilitating condition, which affects Australians of all ages. Despite the negative impacts of incontinence on health, wellbeing and ability to participate fully in society, incontinence has not yet been recognised as a major health issue and accorded priority focus in health policy and services. Indeed, it is frequently completely overlooked. To illustrate, CHA has recently had to make the case for including incontinence in the forthcoming, updated, clinical guidelines on dementia care despite the evidence that incontinence i.e. the leakage of urine or faeces<sup>1</sup> contributes to the overburdening of family carers and is a significant factor in the decision for people with dementia to move into a long-term care placement.<sup>2 3</sup>

### The Policy Problem

There is a paucity of robust data of the prevalence of incontinence in the Australian population. Gaps in data and information contribute to the well documented stigma and silence on this issue and obstruct progress on improving the continence health of the population. CHA believes that it is time to close the damaging gaps in information. This is required to challenge the entrenched stigma surrounding incontinence across the lifespan and the resulting silence, lack of service pathways and poor quality of life for people who live with the conditions. Recognition of incontinence as a long-term health condition will enable renewed focus in policy, research, clinical guideline development and investment in high quality and evidence-based services.

### Incontinence is a chronic condition: the facts

#### Prevalence of Incontinence

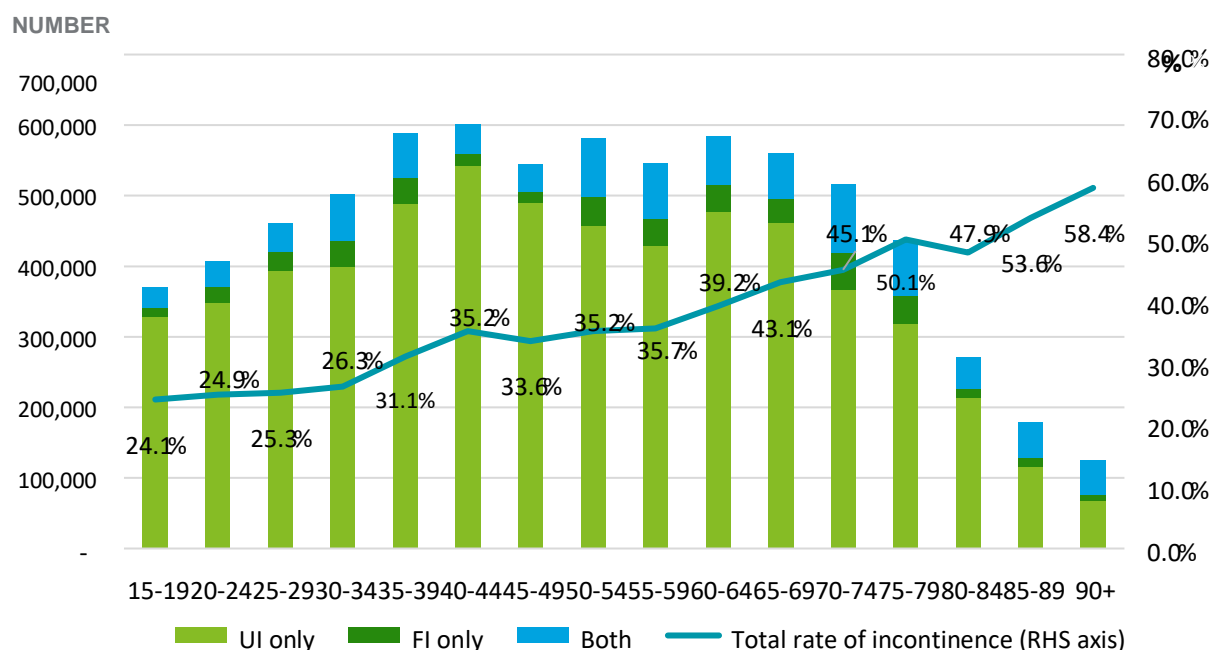
Incontinence is a highly prevalent but under-recognised public health problem affecting Australians of all ages. In 2023, Deloitte Access Economics, in a report commissioned by CHA, estimated that over 7 million Australians, aged 15 or over, experienced some level of urinary or faecal incontinence.<sup>4</sup>

2.4 million men (33% of the total population of men) and 4.8 million women (67% of the total population of women) had some degree of urinary and/or faecal incontinence (UI / FI) in 2023. This is an overall increase of 53% since 2010. These figures are likely to be underestimates as incontinence is frequently under-reported to healthcare services by those affected and often misdiagnosed or not diagnosed by clinicians. These figures reflect those identified in a systematic review of the evidence for pelvic floor

health and dysfunction conducted by the Trezona Consulting Group for Continence Health Australia in 2023.<sup>5</sup>

While the prevalence rate of incontinence increases with age (particularly for those 75 years and over), 71% of people with incontinence are 65 years and younger (See Chart 1 below). Urinary incontinence (UI) is much more prevalent than faecal incontinence. People living in residential care experience incontinence at higher rates than the general population. Of residential aged care residents, 70.9% experience UI and/or faecal incontinence (FI). Looking ahead, the projected number of Australians living with some degree of UI/FI is estimated to rise by 8.6 million (34.1% of the 2032 population) in 2032 based on the expected changes in age profile of the Australian population (all figures from Deloitte Access Economics, 2023).

**Chart 1. Prevalence of Incontinence in Australia in 2023 by Age and type**



Source: Deloitte based on ABS (2023),<sup>142</sup> ABS (2019),<sup>143</sup> Sharma et al. (2016),<sup>144</sup> Linde et al. (2016),<sup>145</sup> Botlero et al. (2009)<sup>146</sup> Hawthorne (2006),<sup>147</sup> ACFI (2009).<sup>148</sup>

## Severe Incontinence

The Australian Institute for Health and Welfare (AIHW), in a [summary](#) published in 2016, cited the following figures for prevalence of severe incontinence from the 2013 report [Incontinence in Australia](#). In 2009, 316,500 people (1.5% of the Australian population) experienced severe incontinence.<sup>6</sup> Of these people, 91.0% also had a severe or profound core activity limitation, indicating they had high-care needs. About 1 in every 14 people aged 65 and over (7.2%) and nearly 1 in 4 people aged 85 and over (24.5%) experienced severe incontinence, compared with 1 in 166 people aged under 65 (0.6%). The prevalence of severe incontinence was higher in females (2.0%) than males (1.0%). About 72,900 primary carers provided help with managing someone else's incontinence— 4 in 5 carers were female (81.2%), and 3 in 4 spent 40 hours or more per week caring (73.0%) (AIHW, 2013). These figures are now over ten years old and require updating.

Avery et al (2021) report that 9.4% of women responding to the 2001 South Australian Health Omnibus Survey, a representative sample of the adult South Australian population, reported severe incontinence. Respondents with any UI, who considered their condition to be very or moderately serious, were more likely to report severe incontinence. Women whose lifestyle was limited by incontinence were more likely to perceive their condition to be very serious. Together, severity and limitations to lifestyle were predictors of women perceiving that their incontinence was moderate to very serious.<sup>7</sup>

## Self-reported continence health needs

Data from a nationally representative survey of the public commissioned by CHA to gauge levels of public awareness and attitudes towards incontinence adds additional detail to the data on prevalence (n=2000) (CH

A, 2024).<sup>8</sup> The survey included people who have, or have had, incontinence and carers.

See Box 1 Below.

### Box 1. The Incidence of incontinence

#### Self-Reported Continence Health Needs

- 43% % of Australians have experienced some bladder or bowel leakage.
- Twice as many women experience some bladder or bowel leakage compared to men.
- 77% of those who currently have incontinence & 82% of those who have had incontinence had urinary incontinence
- 11% of respondents reported that they have had faecal incontinence and 10% reported that they were currently experiencing both faecal and urinary incontinence
- 29% of carers reported that they were currently caring for someone with incontinence. Of these 31% reported that they were caring for a person with both urinary and faecal incontinence
- Incontinence increases with age, with 80% being aged 40 plus, 60% aged 50 plus and 39% aged 60 plus.
- Four in ten of those currently experiencing incontinence have given birth to one or more children
- 16% have a physical disability and 14% have been diagnosed as having incontinence.
- Every at-risk group, including parous women, women who have had a hysterectomy, the elderly, men post-prostate surgery, people living with disabilities including intellectual or cognitive impairment demonstrated higher rates of incontinence than the general population.

### Box 1. National Consumer Survey 2024: Source: Continence Health Australia, 2024

## Incidence of incontinence in specific populations

### Aboriginal and Torres Strait Islander people

Evidence is limited about the incidence of incontinence among Aboriginal and Torres Strait Islander people and results are mixed. While some groups have higher risk factors for incontinence, additional research is needed to know whether this translates to higher prevalence. Benness and Manning (1999)<sup>9</sup> reported an overall urinary incontinence prevalence of 54% in a sample of 281 community-dwelling, non-urban Indigenous women. Half of the women (49%) experienced stress incontinence. LoGiudice et al. (2010) reported a much lower rate of incontinence in their sample of 363 Indigenous Australians aged over 45 (9%), however, the authors suggest that this is an underestimate of the true value because the methods used to determine incontinence had not been tested for the Indigenous population concerned.<sup>10</sup> These authors suggest that falls, urinary incontinence and pain are common in older indigenous people living in remote regions and that *'the presence of these syndromes in ages over 45 may be due to accumulation of health insults during the life course'*.

More recent studies indicate that prevalence and incidence rates of urinary incontinence in Aboriginal Australians are high and are associated with the key risk factors of older age and female sex. Urinary and stress incontinence are both highly prevalent.<sup>11</sup> There is evidence of high levels of shame and underreporting of these conditions in the Aboriginal population.<sup>12 13</sup>

AIHW figures indicate that the Indigenous population experiences many chronic conditions at a higher rate than the non-Indigenous population, including conditions that are risk factors for incontinence.<sup>14</sup> Diabetes is 3 times as common in Indigenous people than non-Indigenous people. Obesity is almost twice as common in Indigenous people (33.6%) than non-Indigenous people (17.9%).<sup>15</sup> Dementia is more common in the Indigenous population than the non-Indigenous population, with one study citing

a prevalence of 12.4% in Indigenous people aged 45 and older living in Western Australia—5 times greater than in the non-Indigenous population.<sup>16</sup> These conditions are risk factors for incontinence.

Despite limited research regarding the Indigenous population and incontinence, the higher rates of risk factors in this population supports the proposition that there may be a higher prevalence of incontinence. Addressing the research gap in this area is an urgent national challenge.

### Culturally and linguistically diverse people

The experience of incontinence in people from culturally and linguistically diverse (CALD) communities can differ depending on their cultural practices, English-language abilities and health literacy skills. Prevalence rates are also variable. For example, in people aged 60 and older in the United States, the prevalence of urinary incontinence was higher in non-Hispanic white women (41%) than non-Hispanic black (20%) or Mexican-American women (36%), while non-Hispanic black men had the highest prevalence of incontinence (21%) compared with non-Hispanic white (16%) and Mexican-American men (14%).<sup>17 18</sup> An equivalent study comparing the prevalence of incontinence in people from different cultural backgrounds has not been conducted in Australia although the AIHW (2013 & 2016) and others provide evidence that culture and belief systems may be implicated in varying kinds of continence health challenges.<sup>19</sup>

Results from a large community survey undertaken by CHA in 2017 showed that CALD respondents were slightly less likely to experience incontinence than the general population.<sup>20</sup> However, they were more likely to avoid discussing incontinence with their family and friends, possibly indicating a level of culturally influenced silence on this issue.<sup>21 22</sup>

In 2012, CHA started an incontinence education and awareness project targeting [CALD communities](#). The project aims to develop effective engagement with CALD communities to improve their awareness of incontinence and encourage help-seeking behaviours.

### Lesbian, gay, bi-sexual, transgender, queer, intersex and asexual populations

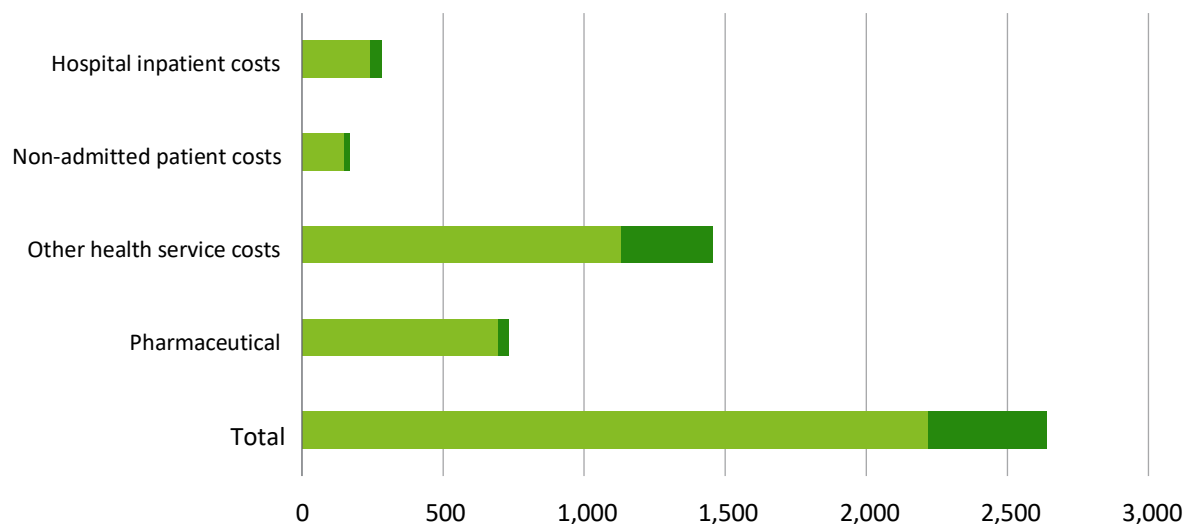
Research regarding the continence health needs of the LGBTQIA+ population is scarce, particularly in relation to LGBTQIA+ elders,<sup>23</sup> but studies indicate that specific groups within the LGBTQIA+ population may be at increased risk of incontinence.<sup>24</sup> There is some evidence that people who have had gender reassignment surgery may be at increased risk of incontinence.<sup>25 26 27</sup>

Concerns about the gaps in research knowledge are compounded by evidence from the third [national survey](#) on the health and wellbeing of gay, lesbian, bisexual and transgender, queer, intersex and asexual Australians completed in 2020. LGBTQIA+ Australians experience high rates of discrimination and mental ill health and occasionally or usually hide their sexuality or gender identity when accessing services.<sup>28</sup> Several studies provide evidence that clinicians can have negative attitudes towards people who are sex or gender diverse.<sup>29 30</sup> A national survey of transgender adults conducted in 2017/18 identified a wide range of barriers faced by transgender individuals including widespread discrimination and unemployment, which contribute to health inequity and prevalent mental health conditions.<sup>31</sup> In the absence of robust research in this area, it is only possible to speculate that LGBTQIA+ people with incontinence continue to face double jeopardy; concealing their continence health needs as well as sexual orientation in their interactions with health services.

### Impacts on Adult Mental Health & Wellbeing

Deloitte Access Economics estimate 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. See Chart 2 below. 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 2: 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 CHA's 2024 Consumer Survey which indicated that there is a substantial impact on the mental health of respondents who live with incontinence. See Chart 3 below.

**Chart 3: Reasons why People Living with Incontinence Report Poor Health**

2024 themes (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 Health Australia. National Consumer Survey 2024

There is growing evidence of the associations between incontinence and psychosocial factors, including depression.

In summary the literature identifies the following:

#### Wellbeing Impacts:

- **Quality of Life:** the constant struggle to manage incontinence can significantly affect an individual's overall quality of life, including relationships, work performance, and emotional well-being. <sup>32 33</sup> There is evidence that incontinence can lead to psychological distress and depressive symptoms. <sup>34</sup>
- **Loneliness:** People with incontinence are at higher risk of loneliness. <sup>35 36</sup>

- **Fear of Embarrassment:** People experiencing incontinence often fear public embarrassment or stigma related to leakage episodes. This fear can lead to anxiety and avoidance of social situations, ultimately resulting in social withdrawal and isolation.<sup>37, 38</sup>
- **Mortality:** Strikingly, urinary incontinence is also a predictor of higher mortality.<sup>39</sup>

## Association with Anxiety and Depression

- **Prevalence:** Studies show a strong association between urinary incontinence (UI) and both anxiety and depression. A Norwegian study found that moderate to severe anxiety or depression increased the prevalence of UI from 27.6% to 37.8% for anxiety and from 28.0% to 43.7% for depression.<sup>40</sup>
- 30% of women with incontinence will also suffer from depression,<sup>41</sup> which is three times more likely than the general population.<sup>42</sup>
- A cross-sectional study evaluated the relationship between urinary incontinence (UI) and depression among men.<sup>43</sup> The odds of depression were significantly higher for men with UI: Compared to no UI, the odds were 4.46 for mixed UI, 3.15 for stress UI, and 2.43 for urge UI.
- **Severity:** The severity of UI is correlated with higher odds of depression. Severe UI was associated with an odds ratio of 2.04 for depression compared to no UI.<sup>44</sup> The odds increased with more severe UI (e.g., very severe UI had an odds ratio of 3.85 compared to slight UI).<sup>45</sup>
- **Chronic Stress:** The ongoing stress of managing incontinence can contribute to the development of anxiety disorders.<sup>46 47</sup>
- **Biological Mechanisms:** Reduced serotonin levels and inflammation (linked to anxiety and depression) may also affect bladder functioning.<sup>48</sup>

## Anxiety and Functional Impairment

- **Increased anxiety:** Severe UI can lead to a four-fold increase in the prevalence of anxiety, particularly when it impairs daily functioning.<sup>49 50</sup>

## Impact of Medications

- **Antidepressants:** The use of antidepressants is associated with an increased prevalence of UI. However, the use of anxiolytics was found to be associated with less UI.<sup>51</sup>
- **Medications:** Some medications used to treat mental health conditions might cause urge incontinence or reduce the bladder sensation that signals the need for urination.<sup>52</sup>

## Impacts on the Health & Wellbeing of 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.<sup>53</sup> Lack of appropriate support and the general silence regarding the problem, which is still considered a taboo by many, aggravate the carers' situation.<sup>54</sup>

Continence Health Australia's Consumer Survey (2024) provides additional insight into the multifactorial, nature of the burden faced by carers. See Table 1 below

**Table 1. Impact on The Health & Wellbeing of Carers**

<b>Carers</b>	<ul style="list-style-type: none"> <li>• 30% of Australians currently care for or have cared in the past for someone who has incontinence.</li> <li>• 44% of carers say that caring for someone with incontinence impacts their mental health and well-being</li> </ul>	<ul style="list-style-type: none"> <li>• 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.</li> </ul>
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	<p>and makes them less confident to leave the house.</p> <ul style="list-style-type: none"> <li>• 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).</li> <li>• 12% of carers indicated it affects their mental health and wellbeing.</li> <li>• Carers are far more likely to have incontinence now (21%) or in the past (13%) than those who never had it (4%).</li> <li>• 52% of the care is provided by a spouse or partner.</li> <li>• 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).</li> <li>• 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).</li> <li>• Those more likely to receive care/support for incontinence (14%) are current or past carers (23%) than others (6%).</li> <li>• 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.</li> <li>• Nearly half of carers cited some financial impact (12% significantly impacted). The 2022 survey found that 7% of carers struggled</li> </ul>	<ul style="list-style-type: none"> <li>• Caring for <ul style="list-style-type: none"> <li>- Parent or parent-in-law 42%</li> <li>- Grandparent 22%</li> <li>- Spouse/partner 18%</li> </ul> </li> <li>• 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 GP or family doctor. In contrast, 23% did not discuss it with anyone.</li> <li>• 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.</li> <li>• Impact on caring for someone: <ul style="list-style-type: none"> <li>Feel supported to participate in community activities 64%</li> <li>Less confident to leave home 46%</li> <li>Affects my mental health and wellbeing 51%</li> <li>Prevents going about day-to-day activities 46%</li> <li>Impacts my relationship with family and friends 38%</li> </ul> </li> </ul>
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	financially, and 42% reported some impact.	
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Source: CHA National Consumer Survey, 2024

## Impacts on Children's Mental Health and Wellbeing

Continence problems are common in childhood and often persist into adolescence. For instance, around 3% of 14-year-olds have daytime urinary incontinence and 2.5% experience bedwetting.<sup>55</sup>

- According to data collected in the first full year of school by teachers, through the Australian Early Development Census (AEDC),<sup>56</sup> 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).<sup>1</sup>
- Young people with incontinence often feel pessimistic about their condition and they report experiencing shame, social isolation, peer victimisation, restricted social lives, and disrupted education.<sup>57 58</sup>
- Many clinicians are unaware of the wider issues affecting adolescents with incontinence, leading to negative clinical care experiences and inadequate treatment.<sup>59</sup>
- The impacts of incontinence on the daily lives of young people place them at an increased risk of developing mental health problems. A recent study (2023), based on data from the Avon Longitudinal Study of Parents and Children, found that young people with incontinence are at greater risk of developing mental health problems in early adulthood.<sup>60</sup>
- There is also evidence that mental health problems can increase the risk of new onset incontinence in children<sup>61</sup> and have an adverse effect on treatment adherence.<sup>62</sup>

These findings have important clinical implications because they highlight the need for mental health support for young people with incontinence, which is currently lacking.

## Risk Factors for Incontinence

Incontinence and other disorders affecting the bowel and bladder are extremely complex health issues with multifactorial determinants. The voluminous report of the [7<sup>th</sup> International Consultation on Incontinence](#) (2023) provides a textbook of high-quality studies for clinicians and others interested in understanding the epidemiology and clinical aspects of these conditions.

The Trezona systematic review of the evidence on pelvic floor dysfunction (2024), commissioned by CHA cites over 70 studies addressing the range of risk factors potentially involved in these complex conditions. This review notes several of the ubiquitous problems affecting research on incontinence across the board, including the low quality of many research studies. Reasons for this include the extreme heterogeneity of the studies in terms of study design, sample sizes, inclusion criteria, assessment of outcomes and inconsistencies in definitions of incontinence. These challenges were also noted in the Deloitte report. Trezona suggests that the factors which may contribute to incontinence can only be considered associative rather than causal given the lack of research in this area. (p22).

Various attempts have been made to summarise evidence to provide a classification of potential risk factors.

The AIHW suggests that risk factors for incontinence are stratified based on the basic processes in the body that cause incontinence.<sup>63</sup> This system suggests five categories:

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<sup>1</sup> Note that this data is not a medical diagnosis, it is based on teacher observations and has not been validated as a measure of child development.]

- Physical status (for example, age,<sup>2</sup> sex, obesity),
- genetic factors (for example, family history),
- neuropsychiatric conditions (for example, multiple sclerosis, dementia, depression, stroke,
- diabetic neuropathy),
- trauma (for example, childbirth, prostatectomy), and associated conditions (for example, diarrhoea, inflammatory bowel disease, menopause, smoking, constipation, urinary tract infections).

These categories are limited and include overlaps, with some risk factors falling in two categories. It is important to note that some of these risk factors are modifiable and some are not. <sup>64</sup> Trezona provides a broader classification beyond individual-level factors (sex, gender, age, weight, physical activity levels, overall health status) to address the following:

- **Environmental and social determinants** - sociocultural environmental factors influencing toileting behaviours, pelvic health knowledge, attitudes and awareness among professionals and the public, inequities in care and treatment, stigma and patriarchal attitudes.
- **Health System Factors** - workforce capacity and capabilities, the attitudes and beliefs of health professionals, inadequate communication and information provision, discrimination within healthcare systems towards marginalised groups of women, limited resources in acute and residential care settings leading to poor quality care

### Economic Cost of Incontinence

Incontinence is costly. In 2023 the total cost of incontinence in Australia was \$66.6 billion, with an additional \$33.8 billion in lost wellbeing. The largest proportion of costs were due to lost productivity, as a large proportion of people (71%) are in the working-age population and those living in the community with incontinence requiring formal care.

Chronic diseases and obesity continue to rise in Australia's expanding and ageing population. This will impact on the prevalence of incontinence without effective policy action focused on better prevention and management.

See Table 2 below.

**Table 2 . Economic cost of incontinence in Australia in 2023 (millions)**

	UI (\$millions)			FI (\$millions)			Total (\$millions)	% of total
	Men	Women	Total UI	Men	Women	Total FI		
Health system	761.4	1,457.8	2,219.3	222.4	198.2	420.5	2,639.8	4.0

<sup>2</sup> It is important to note that incontinence is not an inevitable part of ageing. However, as reported by the AIHW (Australian *incontinence data: analysis and development 2006*), age is the most commonly cited factor associated with incontinence. <sup>2</sup>

Other financial	330.4	590.5	920.9	123.1	167.6	290.7	1,211.6	1.8
Productivity	16,692.1	29,783.4	46,475.5	4,462.7	3,007.2	7,469.9	53,945.4	81.0
Efficiency losses	2,333.3	5,207.3	7,540.6	665.5	591.0	1,256.5	58,797.0	13.2

Source: Deloitte. 2023

## Conclusion

There is a bi-directional relationship between incontinence and chronic diseases. The social and physical isolation caused by severe incontinence can, for example, increase the risk of developing chronic diseases due to reduced physical activity and increased sedentary behaviours.<sup>5</sup> Additional research is required to clarify the complex linkages between incontinence and other chronic diseases as risk factors can vary depending on the type of incontinence, gender, age, ethnicity, culture and family history. **However, the evidence that is already available strongly suggests that it is time for a new understanding of incontinence as a significant public health issue in its own right and not, merely, as a symptom of other conditions.**

As chronic diseases and obesity continue to rise in Australia's expanding and ageing population, there will be an accompanying increase in the prevalence of incontinence without effective policy action focused on better prevention and management. Continence health must be integrated in all national and local chronic disease prevention strategies. Recognition of incontinence as a chronic disease is the first, essential step.

## Recommendations

Continence Health Australia requests the Australian Federal Government to consider the following steps towards achieving this.

1. **Recognise incontinence as a long term health condition** and not just a symptom of other conditions or an unavoidable consequence of certain life transitions.
2. **Commit to the development of a National Continence Plan for 21st century Australia.** This plan should address the distinct and separate needs of women, men and minority groups and communities.
3. Request the Australian Bureau of Statistics to **embed questions on continence health in the National Health Survey** to ensure that information about incidence, prevalence and impacts are updated regularly.
4. Request the National Medical and Health Research Council to **establish incontinence as a research priority to accompany the development and implementation of a new National Continence Plan.**

- <sup>1</sup> Abrams, P., Cardozo, L., Khoury, S. and Wein, A.J. eds., 2013. *Incontinence: 2013*. International Consultation on Urological Diseases.
- <sup>2</sup> Luppia, M., Luck, T., Brähler, E., König, H.H. and Riedel-Heller, S.G., 2008. Prediction of institutionalisation in dementia: A systematic review. *Dementia and geriatric cognitive disorders*, 26(1), pp.65-78.
- <sup>3</sup> Young, Y., Kalamaras, J., Kelly, L., Hornick, D. and Yucel, R., 2015. Is aging in place delaying nursing home admission? *Journal of the American Medical Directors Association*, 16(10), pp.900-e1.
- <sup>4</sup> Deloitte Access Economics. 2023. Economic Cost of Incontinence in Australia, Continence Foundation of Australia. (In press)
- <sup>5</sup> Trezona Consulting Group. 2023. Pelvic Floor Health. Evidence Review. Continence Foundation of Australia. (in press)
- <sup>6</sup> Australian Institute of Health and Welfare 2013. Incontinence in Australia. Cat. no. DIS 61. Canberra: AIHW.
- <sup>7</sup> Avery, J.C., Gill, T.K., Taylor, A.W. and Stocks, N.P., 2014. Urinary incontinence: severity, perceptions and population prevalence in Australian women. *The Australian and New Zealand Continence Journal*, 20(1), pp.7-13.
- <sup>8</sup> Continence Foundation of Australia (2017), Continence in the Australian Community: Awareness and Attitudes Survey 2017. Continence Foundation of Australia Internal Report. Unpublished.
- <sup>9</sup> Benness, C. and Manning, J., 1999. Urinary incontinence in Australian Aboriginal women. In *8Th National Continence Foundation of Australia Conference, Sydney NSW*.
- <sup>10</sup> LoGiudice, D.C., Smith, K., Atkinson, D., Dwyer, A., Lautenschlager, N., Almeida, O.A. and Flicker, L., 2012. Preliminary evaluation of the prevalence of falls, pain and urinary incontinence in remote living Indigenous Australians over the age of 45 years. *Internal medicine journal*, 42(6), pp.e102-e107.
- <sup>11</sup> Smith, K., Sutherland, A., Hyde, Z., Crawford, R., Dwyer, A., Malay, R., Skeaf, L., Flicker, L., Atkinson, D. and LoGiudice, D., 2019. Assessment, incidence and factors associated with urinary incontinence in older Aboriginal Australians. *Internal Medicine Journal*, 49(9), pp.1111-1118.
- <sup>12</sup> Ip, V. and Busuttil Leaver, R., 2007. Urinary incontinence—meeting a transcultural challenge in Sydney, Australia. *International Journal of Urological Nursing*, 1(3), pp.133-137.
- <sup>13</sup> Clarke, M., Whitson, N., Williams, C. and Robson, S.J., 2021. A silent burden—prolapse, incontinence, and infertility in Australian Aboriginal and Torres Strait Islander women: A systematic search and narrative review. *International Journal of Gynecology & Obstetrics*, 155(2), pp.268-274.
- <sup>14</sup> Australian Institute of Health and Welfare 2016. Australia's health 2016. Australia's health series no. 15. Cat. no. AUS 199. Canberra: AIHW.
- <sup>15</sup> ABS 2013, Census of Population and Housing: *Socio-economic Indexes for Areas (SEIFA), Australia, 2011*, cat. 2033.0.55.001, ABS, Canberra
- <sup>16</sup> Smith, K., Flicker, L., Dwyer, A., Atkinson, D., Almeida, O.P., Lautenschlager, N.T. and LoGiudice, D., 2010. Factors associated with dementia in Aboriginal Australians. *Australian and New Zealand Journal of Psychiatry*, 44(10), pp.888-893.
- <sup>17</sup> Anger JT, Saigal CS, Litwin MS for the Urologic Diseases America Project. The prevalence of urinary incontinence among community dwelling adult women: Results from the National Health and Nutrition Examination Survey. *J Urol*. 2006;175:601–604
- <sup>18</sup> Anger, J.T., Saigal, C.S., Stothers, L., Thom, D.H., Rodríguez, L.V., Litwin, M.S. and Urologic Diseases of America Project, 2006. The prevalence of urinary incontinence among community dwelling men: results from the National Health and Nutrition Examination survey. *The Journal of urology*, 176(5), pp.2103-2108.
- <sup>19</sup> Ip, V. and Busuttil Leaver, R., 2007. Urinary incontinence—meeting a transcultural challenge in Sydney, Australia. *International Journal of Urological Nursing*, 1(3), pp.133-137.
- <sup>20</sup> Continence Foundation of Australia. 2017. Continence in the Australian Community: Awareness and Attitudes Survey 2017. Continence Foundation of Australia Internal Report. Unpublished.
- <sup>21</sup> Wang, C., Li, J., Wan, X., Wang, X., Kane, R.L. and Wang, K., 2015. Effects of stigma on Chinese women's attitudes towards seeking treatment for urinary incontinence. *Journal of clinical nursing*, 24(7-8), pp.1112-1121.
- <sup>22</sup> Hoogsteyns, M. and van der Horst, H., 2015. How to live with a taboo instead of 'breaking it'. Alternative empowerment strategies of people with incontinence. *Health Sociology Review*, 24(1), pp.38-47.
- <sup>23</sup> Hillman, J., 2017. The sexuality and sexual health of LGBT elders. *Annual Review of Gerontology and Geriatrics*, 37(1), pp.13-26.
- <sup>24</sup> Truesdale, M.D., Breyer, B.N. and Shindel, A.W., 2016. Urologic Issues in LGBT Health. In *Lesbian, Gay, Bisexual, and Transgender Healthcare* (pp. 289-307). Springer, Cham.
- <sup>25</sup> Hoebeke, P., Selvaggi, G., Ceulemans, P., De Cuyper, G., T'Sjoen, G., Weyers, S., Decaestecker, K. and Monstrey, S., 2005. Impact of sex reassignment surgery on lower urinary tract function. *European urology*, 47(3), pp.398-402.
- <sup>26</sup> Williamson, C., 2010. Providing care to transgender persons: a clinical approach to primary care, hormones, and HIV management. *Journal of the Association of Nurses in AIDS Care*, 21(3), pp.221-229.
- <sup>27</sup> van Trotsenburg, M.A., 2009. Gynecological aspects of transgender healthcare. *International Journal of Transgenderism*, 11(4), pp.238-246.
- <sup>28</sup> Hill, A. O., Bourne, A., McNair, R., Carman, M. & Lyons, A. (2020). Private Lives 3: The health and wellbeing of LGBTIQ people in Australia. ARCSHS Monograph Series No. 122. Melbourne, Australia: Australian Research Centre in Sex, Health and Society, La Trobe University.
- <sup>29</sup> Eliason, M.J., Dibble, S. and DeJoseph, J., 2010. Nursing's silence on lesbian, gay, bisexual, and transgender issues: The need for emancipatory efforts. *Advances in Nursing Science*, 33(3), pp.206-218.

- <sup>30</sup> Durso, L.E. and Meyer, I.H., 2013. Patterns and predictors of disclosure of sexual orientation to healthcare providers among lesbians, gay men, and bisexuals. *Sexuality Research and Social Policy*, 10(1), pp.35-42.
- <sup>31</sup> Bretherton, I., Thrower, E., Zwickl, S., Wong, A., Chetcuti, D., Grossmann, M., Zajac, J.D. and Cheung, A.S., 2021. The health and well-being of transgender Australians: a national community survey. *LGBT health*, 8(1), pp.42-49.
- <sup>32</sup> Debus, G. et al. (2015). Psychosomatic Aspects of Urinary Incontinence in Women. *Geburtshilfe Frauenheilkd.* <https://dx.doi.org/10.1055/s-0034-1396257>. <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4361165/>
- <sup>33</sup> Kuoch, K. L. J. et al. (2019). Urinary and Fecal Incontinence: Psychological Factors and Management Recommendations. *New Zealand Medical Journal.* <https://journal.nzma.org.nz/journal-articles/urinary-and-faecal-incontinence-psychological-factors-and-management-recommendations>
- <sup>34</sup> Wu, S., Wu, F. Association of urinary incontinence with depression among men: a cross-sectional study. *BMC Public Health* 23, 944 (2023). <https://doi.org/10.1186/s12889-023-15961-9>
- <sup>35</sup> <https://www.tena.co.uk/articles/mental-health-and-incontinence>
- <sup>36</sup> Stickley, A. et al. (2017). Urinary Incontinence, Mental Health, and Loneliness Among Community-Dwelling Older Adults in Ireland. *BMC Urology.* <https://doi.org/10.1186/s12894-017-0214-6>
- <sup>37</sup> <https://bmcurol.biomedcentral.com/articles/10.1186/s12894-017-0214-6>
- <sup>38</sup> <https://nafc.org/bhealth-blog/understanding-the-connection-between-mental-health-and-incontinence-in-women/>
- <sup>39</sup> Debus G, Kästner R. Psychosomatic Aspects of Urinary Incontinence in Women. *Geburtshilfe Frauenheilkd.* 2015 Feb;75(2):165-169. doi: 10.1055/s-0034-1396257. PMID: 25797959; PMCID: PMC4361165.
- <sup>40</sup> Shah, J., 2022. The Impact of Urinary Incontinence on Men's Health. In *Men's Health and Wellbeing* (pp. 85-94). Cham: Springer International Publishing.
- <sup>41</sup> Felde, G., Engeland, A. & Hunskaar, S. Urinary incontinence associated with anxiety and depression: the impact of psychotropic drugs in a cross-sectional study from the Norwegian HUNT study. *BMC Psychiatry* 20, 521 (2020). <https://doi.org/10.1186/s12888-020-02922-4>
- <sup>42</sup> Morrison, L.M., Morrison, M., Small, D.R. and Glen, E.S., 1991. Psychiatric aspects of female incontinence. *International Urogynecology Journal*, 2, pp.69-72.
- <sup>43</sup> Melville, J.L., Walker, E., Katon, W., Lentz, G., Miller, J. and Fenner, D., 2002. Prevalence of comorbid psychiatric illness and its impact on symptom perception, quality of life, and functional status in women with urinary incontinence. *American journal of obstetrics and gynecology*, 187(1), pp.80-87.
- <sup>44</sup> Wu, S. and Wu, F., 2023. Association of urinary incontinence with depression among men: a cross-sectional study. *BMC public health*, 23(1), p.944.
- <sup>45</sup> Felde, G., Engeland, A. & Hunskaar, S. Urinary incontinence associated with anxiety and depression: the impact of psychotropic drugs in a cross-sectional study from the Norwegian HUNT study. *BMC Psychiatry* 20, 521 (2020). <https://doi.org/10.1186/s12888-020-02922-4>
- <sup>46</sup> Wu, S., Wu, F. Association of urinary incontinence with depression among men: a cross-sectional study. *BMC Public Health* 23, 944 (2023). <https://doi.org/10.1186/s12889-023-15961-9>
- <sup>47</sup> Siddiqui, N. Y. et al. (2018). Mental Health, Sleep and Physical Function in Treatment Seeking Women with Urinary Incontinence. *The Journal of Urology.* <https://doi.org/10.1016/j.juro.2018.04.076>. <https://www.auajournals.org/doi/10.1016/j.juro.2018.04.076>
- <sup>48</sup> Mehr, A.A., Kreder, K.J., Lutgendorf, S.K., Ten Eyck, P., Greimann, E.S. and Bradley, C.S., 2022. Daily symptom associations for urinary urgency and anxiety, depression and stress in women with overactive bladder. *International urogynecology journal*, 33(4), pp.841-850.
- <sup>49</sup> [https://www.bristol.ac.uk/media-library/sites/policybristol/briefings-and-reports-pdfs/2023-briefings/PolicyReport89\\_Joinson\\_incontinence\\_mental\\_health.pdf](https://www.bristol.ac.uk/media-library/sites/policybristol/briefings-and-reports-pdfs/2023-briefings/PolicyReport89_Joinson_incontinence_mental_health.pdf)
- <sup>50</sup> Felde, G., Engeland, A. & Hunskaar, S. Urinary incontinence associated with anxiety and depression: the impact of psychotropic drugs in a cross-sectional study from the Norwegian HUNT study. *BMC Psychiatry* 20, 521 (2020). <https://doi.org/10.1186/s12888-020-02922-4>
- <sup>51</sup> Cheng S, Lin D, Hu T, et al. Association of urinary incontinence and depression or anxiety: a meta-analysis. *Journal of International Medical Research.* 2020;48(6). doi:10.1177/0300060520931348
- <sup>52</sup> Felde, G., Engeland, A. & Hunskaar, S. Urinary incontinence associated with anxiety and depression: the impact of psychotropic drugs in a cross-sectional study from the Norwegian HUNT study. *BMC Psychiatry* 20, 521 (2020). <https://doi.org/10.1186/s12888-020-02922-4>
- <sup>53</sup> Hall SA, Maserejian NN, Link CL, Steers WD, McKinlay JB. Are commonly used psychoactive medications associated with lower urinary tract symptoms? *Eur J Clin Pharmacol.* 2012 May;68(5):783-91. doi: 10.1007/s00228-011-1170-9. Epub 2011 Dec 4. PMID: 22138718; PMCID: PMC3538827.
- <sup>54</sup> Talley, K.M., Davis, N.J., Peden-McAlpine, C., Martin, C.L., Weinfurter, E.V. and Wyman, J.F., 2021. Navigating through incontinence: A qualitative systematic review and meta-aggregation of the experiences of family caregivers. *International Journal of Nursing Studies*, 123, p.104062.
- <sup>55</sup> Brittain, K.R. and Shaw, C., 2007. The social consequences of living with and dealing with incontinence—A carers perspective. *Social science & medicine*, 65(6), pp.1274-1283.
- <sup>56</sup> He Brittain, K.R. and Shaw, C., 2007. The social consequences of living with and dealing with incontinence—A carers perspective. *Social science & medicine*, 65(6), pp.1274-1283.
- <sup>57</sup> ron, J., Grzeda, M.T., von Gontard, A., Wright, A. and Joinson, C., 2017. Trajectories of urinary incontinence in childhood and bladder and bowel symptoms in adolescence: prospective cohort study. *BMJ open*, 7(3), p.e014238.

- 
- <sup>56</sup> Australian Children's Education and Care Quality Authority (ACECQA), October 2016. Cited in report on toilet training research. 2023. Commissioned by the Continence Foundation of Australia
- <sup>57</sup> Grzeda MT, Heron J, von Gontard A, Joinson C. Effects of urinary incontinence on psychosocial outcomes in adolescence. *Eur Child Adolesc Psychiatry*. 2017 Jun;26(6):649-658. <http://doi.org/10.1007/s00787-016-0928-0>
- <sup>58</sup> Whale K, Cramer H, Joinson C. Left behind and left out: The impact of the school environment on young people with continence problems. *Br J Health Psychol*. 2018 May;23(2):253-277. <http://doi.org/10.1111/bjhp.12228>
- <sup>59</sup> Whale K, Cramer H, Wright A, Sanders C, Joinson C. 'What does that mean?': a qualitative exploration of the primary and secondary clinical care experiences of young people with continence problems in the UK. *BMJ Open*. 2017 Oct 16;7(10):e015544. <http://doi.org/10.1136/bmjopen-2016-015544>
- <sup>60</sup> Gordon K, Warne N, Heron J, von Gontard A, Joinson C. Continence Problems and Mental Health in Adolescents from a UK Cohort. *Eur Urol*. 2023 May 27:S0302-2838(23)02818-X. <http://doi.org/10.1016/j.eururo.2023.05.013>
- <sup>61</sup> Warne N, Heron J, von Gontard A, Joinson C. Mental health problems, stressful life events and new-onset urinary incontinence in primary school-age children: a prospective cohort study. *Eur Child Adolesc Psychiatry*. 2023 Apr 24. <http://doi.org/10.1007/s00787-023-02211-x>
- <sup>62</sup> Van Herzeele C, De Bruyne P, De Bruyne E, Walle JV. J Pediatr Urol. Challenging factors for enuresis treatment: Psychological problems and non-adherence. 2015 Dec;11(6):308-13. <http://doi.org/10.1016/j.jpuro.2015.04.035>
- <sup>63</sup> Landefeld CS, Bowers BJ, Feld AD, Hartmann KE, Hoffman E, Ingber MJ et al. 2008. National Institutes of Health state-of-the-science conference statement: prevalence of fecal and urinary incontinence in adults. *Annals of Internal Medicine* 148:449–58
- <sup>64</sup> Wagg, A. (2015) Improving Continence around the World. *Nursing Times* <https://www.nursingtimes.net/clinical-archive/continence/improving-continence-care-around-the-world/5085280>. article