



Continenence
Foundation
of Australia

2023 National Consumer Survey Analysis



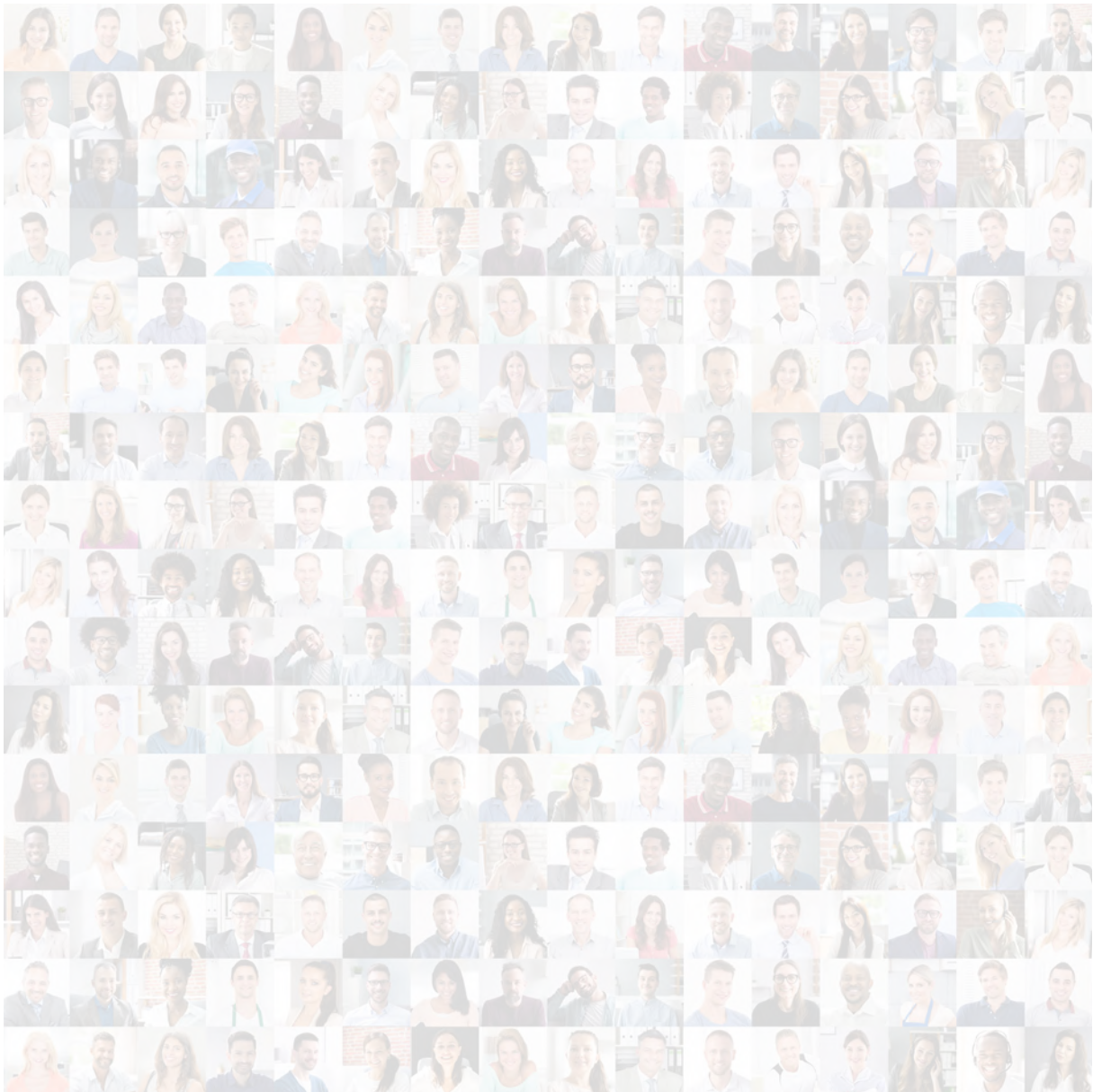
Report prepared February 2024

Introduction

Each year, the Continenence Foundation of Australia conducts a National Consumer Survey to gain insights into the community's perceptions and experience of incontinence, the quality of life and wellbeing of people who experience it, and their carers.

Approximately 2,000 people participated in the survey, broadly representing the Australian population in terms of age, gender and geography.

The following are the key insights from the survey.



Key Insights from the 2023 Survey

Prevalence

- 39% of Australians (24.2% females and 14.8% males) reported currently having or had incontinence in the past. The table shows the breakdown by generation and gender.

Age Group	Females	Males	Total
Interwar 70+ years	11%	6%	17%
Baby Boomers 50-69 years	20.5%	10.3%	30.8%
Gen X 30-49 years	21.5%	14.1%	35.6%
Millennials 18-29 years	9.4%	7.3%	16.7%

- The prevalence of 39% is marginally short of the COVID-19 lockdown period, which recorded a higher average of 43% for 2020 to 2022.

Health and wellbeing

- 40% with incontinence feel it affects their mental health and wellbeing.
- 22% with incontinence feel it affects their relationship with family and friends.
- 46% with incontinence are reluctant to discuss their condition with family and friends. Of these, 44% feel too embarrassed to discuss incontinence.
- 10% have indicated they avoid going out with people due to incontinence.

Key Thematic Insights

Awareness

About incontinence

- 61% of respondents said they do not know anyone who has/had incontinence.
- About 71% of respondents believe that people aged over 65 years are more likely to experience incontinence. Similarly, 63% believe women who have given birth, and 57% believe that men with prostate problems are more likely to experience incontinence.
- Nearly 43% have indicated they have never been worried or concerned about incontinence.
- In recent years, over 60% say they have become more aware of incontinence and accepting people who have it.
- Prominent among reasons for not talking to a health professional about incontinence is the view it's not severe enough/considered to be a major issue, embarrassment or a preference not to talk about it.

Managing incontinence

- Help-seeking behaviour appears to have increased, with the majority of those with incontinence (67%) as well as their carers (81%) having discussed the condition with a health professional. This is an increase from 2022, which found that only 44% of those who currently experience incontinence had not contacted a health professional.
- More than one-third (37%) of those who have not talked to family, relatives or friends about incontinence say that nothing has prevented them from discussing it. A similar proportion admits they would be too embarrassed to do so (39%).
- Embarrassment is the main barrier and may also be an underlying factor for the 22% who say they do not talk about 'personal things', and 19% say they would not know how to raise it. A few are unsure and believe nothing would help them to have such discussions, while others feel raising awareness and communications to normalise conversations about this issue may make a difference.

Community perceptions and awareness

- 74% believe that community awareness around bladder and bowel health is lacking.
- 54% who have or had experienced incontinence have discussed it with family/friends in mostly positive terms.
- 76% believe incontinence is associated with old age (47% in 2022), and 56% believe it is inevitable after giving birth.
- 42% believe advice and information on incontinence is easy to find.
- 69% have become more accepting of people who experience incontinence, whilst 61% say that over the last 1 to 2 years, they have become more aware of incontinence.

Employment

- 30% of those with incontinence work full time, 18% part time, 6% casually and 6% are seeking work. Just under half of those working have required and received support at work. Only 5% indicated that assistance is needed but not provided.
- Three in ten (30%) of those with incontinence who work part time or casually or who are seeking work tell us that this condition affects their employment status. Caring for someone with incontinence affects the employment status of 39% of respondents.
- For those who have incontinence and are employed, more than four in ten (44%) have experienced some difficulty at work relating to their condition. The most common difficulty is being unable to access appropriate toilets or change facilities easily enough (19%), with almost as many (17%) indicating that their manager is not helpful.
- More than one-third (35%) said their condition had reduced their ability to work in the last three months to a great extent (8%) or some extent (28%). A further 20% answered “only a little” here. Therefore, more than half claim incontinence has negatively impacted their ability to work in the last three months.
- The most common form of assistance provided has been access to appropriate toilets and change facilities (mentioned by 23%), followed by time off for appointments due to ill health (19%).

Carers experience

- 30% of Australians currently care for or have cared in the past for someone who has incontinence.
- 44% of carers say that caring for someone with incontinence impacts their mental health and wellbeing and makes them less confident to leave the house.
- 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).
- 12% of carers indicated it affects their mental health and wellbeing.
- Carers are far more likely to have incontinence now (21%) or in the past (13%) than those who never had it (4%).
- 52% of the care is provided by a spouse or partner.
- 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).
- 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).
- Those more likely to receive care/support for incontinence (14%) are current or past carers (23%) than others (6%).
- 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.
- Nearly half of carers cited some financial impact (12% significantly impacted). The 2022 survey found 7% of such carers struggling financially and 42% reporting some impact.

Experiences of incontinence

- 10% of Australians report that they currently have incontinence and 29% of Australians report that they have experienced incontinence in the past.
- 28% of those who have or had incontinence say they are not in good health combined with 18% of the total sample.
- Of those who have or had incontinence, 29% have experienced it for five or more years, compared with 18% in 2022.
- 58% of females who have experienced incontinence currently or in the past have given birth.
- 40% say that, over the past 12 months, their experience of incontinence has become easier, and 15% say it has become harder.
- Those more likely to receive care/support for incontinence (14%) have had incontinence for less than five years (17%) combined with over five years (9%).

Impact of incontinence

- 42% of people who previously or currently experience incontinence say that it causes them to be less confident to leave the house, a decrease from 49% in 2022.
- 40% say it affects their mental health and wellbeing.
- 23% experience adverse financial impacts to some degree, and 30% say that it affects their employment status, with 56% reporting that it has affected their ability to work in the last three months.

Thinking about your own experience with incontinence

- 49% don't feel comfortable embarking on a long trip without knowing when the first toilet stop will be.
- In the last 12 months, incontinence has become an easier experience for 40% combined with 15% who say it has become harder.
- 46% states one of the most common techniques to manage incontinence is ensuring there are always toilets nearby.
- More than half (55%) have been advised to use pelvic floor muscle exercises to help manage their incontinence. This has been the most effective of quite a few recommendations received. Pelvic floor muscle exercises have been recommended to 72% of females and 27% of males. Advice to use continence products and sanitary pads/liners has also been provided more often to females (32%) than males.
- Many have heeded the advice given, with over three-quarters finding at least one of the recommendations to be effective.
- Pelvic floor muscle exercise advice has been given to 55%, yet only 35% report that this worked best to manage their incontinence. Despite this, pelvic floor muscle exercises rate as the most effective strategy by respondents, with 'no strategies have been effective for helping me manage incontinence' being cited as the next most effective strategy at 24%.

- Self-management is the main reason for not consulting a professional about incontinence, mentioned by 59%, and we could place the 16% who found self-management information themselves. 44% said their incontinence has not been severe enough, while embarrassment has held back 29%. 26% feel it is a normal part of ageing, and 19% expected it to get better on its own.
- The extent to which incontinence can negatively impact people. For some, incontinence has caused reluctance to leave the house (42%), go about daily activities (25%) and affect relationships with family or friends (22%). 40% admit that incontinence affects their mental health and wellbeing. On the plus side, almost half (46%) feel supported to participate in community activities.
- Although 19% have been in situations where appropriate toilets or change facilities were not accessible, not many (6% or less) have encountered discriminatory situations related to work or the behaviour of others like those listed.
- Although only 4% of those who have or had incontinence have struggled financially, 23% have been adversely affected to some degree. Males (29%) and those aged 18-24 (48%) were above average in claiming at least some financial impact.

Discussing incontinence with family and friends

- 46% of those who have or had incontinence say they have not discussed it with their friends or family (compared to 33% in 2022). 39% stated that embarrassment was the reason preventing them from discussing it.
- 64% said talking with their friends and family was mostly positive.
- More than one-third (37%) of those who have not talked to family, relatives or friends about incontinence say nothing has prevented them from having such discussions, but a similar proportion admits they would be too embarrassed to do so (39%). Embarrassment is the main barrier and may also be an underlying factor for the 22% who say they do not talk about personal things and the 19% who state they would not know how to raise it. A few are unsure and believe nothing would help them to have such discussions, while others feel raising awareness and communications to normalise conversations about this issue may make a difference.

Discussing incontinence with a health/continence professional

- The majority of those with incontinence (67%) and carers (81%) have discussed the condition with a health professional and found the advice helpful. This is an increase from 2022 data, which found that 44% of those with incontinence had not contacted a health professional.
- Of those who have not discussed incontinence with a health professional, 29% cited that they did not see it as severe enough to raise.
- 29% said they found talking to their GP very helpful, whilst discussing with a specialist yielded a higher satisfactory rating (39% and 40% found for pelvic health physiotherapist and nurse continence specialist, respectively).
- Among those with incontinence now or in the past, 46% have talked to their GP about it, and 21% have talked to at least one other specialist.
- When consulting a health professional about incontinence, the discussion was initiated by them rather than by the professional (68% to 29%) primarily because they were experiencing the condition.

- If raised by the health professional, several factors may have influenced this, such as caring for someone with incontinence, the professional asking if they had any concerns about it or due to another condition or impending surgery.
- The most efficient way of encouraging discussions with a health professional about incontinence would be initiation by the doctor (mentioned by 50%), while having information displayed about incontinence health would also inspire a sizeable minority (39%).

Other Data Insights

Perception

Perception about incontinence	Percentage who believe it is true
Incontinence is likely to happen with old age	76%
There are exercises that can help prevent or reduce incontinence	75%
People in the community lack awareness about incontinence (bladder and bowel health)	74%
Some incontinence is inevitable after giving birth	56%
I have never been worried or concerned about incontinence	43%
Advice and information on incontinence is easy to find	42%

Perception of groups likely to experience	Percentage who believe it is true
People aged over 65 years	71%
Women who have given birth	63%
Men with prostate problems	57%
People with dementia	47%
People with a physical disability	43%
People who are overweight or obese	35%
Young children aged 6-12 years	12%
People who smoke	11%
People experiencing sleeping difficulties	11%
Adolescents (teenagers)	3%
None of the above	4%

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