

CONTINENCE IN AUSTRALIA A SNAPSHOT

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Continenence
Foundation
of Australia

A report by the
Continenence Foundation of Australia



The Continece Foundation is supported by the Australian Government Department of Health under the National Continece Program and the Health Peak and Advisory Bodies Program.

ABOUT THE CONTINENCE FOUNDATION OF AUSTRALIA

Since 1989, the Continence Foundation of Australia 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 Continence Foundation of Australia promotes bladder and bowel control by:

- working with consumers, professionals, industry and government;
- facilitating access to continence support services;
- providing evidence based information and advice;
- building the capacity and capability of the workforce; and
- supporting research to achieve the Foundation's objectives.

For more information about the Continence Foundation of Australia, visit continence.org.au

FOR MORE INFORMATION ABOUT THIS REPORT

Contact **Rowan Cockerell**, CEO,
Continence Foundation of Australia,
at R.Cockerell@continence.org.au

CONTINENCE IN AUSTRALIA – AT A GLANCE

- Contenance is the ability to have voluntary control over bladder and bowel function. For most people, continence is established in childhood, however some people are born with incontinence and some develop it during their life.
- **38%** of Australians report they have experienced incontinence, with **14%** currently experiencing incontinence, and a further **24%** having experienced some form of incontinence in the past.
- Almost **one-third** of Australians (**31%**) indicated that they can lose control of their bowel or bladder on occasion and **10%** indicate that they frequently lose control of their bladder or bowel.
- There is evidence to suggest that rates of incontinence are increasing. Between 2009 and 2012, the rates of severe incontinence among people with a disability increased by **24%**.
- Incontinence impacts on people's social and emotional wellbeing and their ability to engage with the community, with **39%** of people who experience incontinence indicating that they are less confident in leaving the house, almost one-third (**32%**) suggesting that it affects their mental health and wellbeing and one-quarter (**25%**) indicating that it affects their relationships with family and friends.
- Incontinence is often perceived as normal, with **63%** of people believing that some incontinence was inevitable following child birth and **48%** believing that incontinence is an inevitable part of ageing.
- However, incontinence can be treated and managed and in many cases it can also be cured.
- Both stigma and the perception of incontinence as being normal contribute to people not seeking help for the condition, with a majority (**62%**) of Australians who currently experience incontinence or have experienced it in the past not contacting a health professional regarding the issue.
- Australia has had a strong continence management program, which needs to continue into the future to meet ongoing challenges.

Experience of incontinence



31%

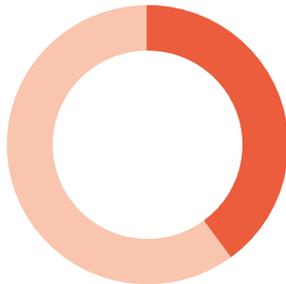
lose control of bowel and bladder



38%

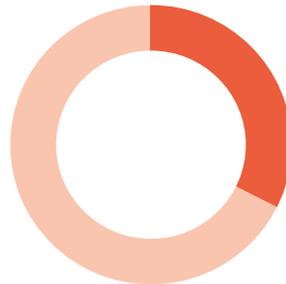
have experienced incontinence

Impacts of incontinence



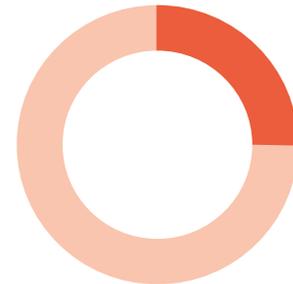
39%

are less confident
leaving the house



32%

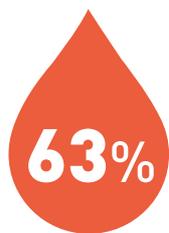
have their mental health
and wellbeing affected



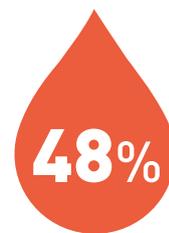
25%

have their relationships with
families and friends affected

Perception of incontinence



believe that incontinence is
inevitable after child birth



believe that incontinence is an
inevitable part of ageing



NATIONALLY

1,997 PEOPLE

WERE SURVEYED TO UNDERSTAND
AUSTRALIANS EXPERIENCE
OF INCONTINENCE.

ABOUT THIS REPORT

This report provides a snapshot of what is known about continence in Australia. The report includes previously unreleased data collected through a nationally representative survey of Australians.

It also draws on data from the Australian Institute of Health and Welfare (AIHW) and Australian Bureau of Statistics (ABS) and information about the current policy environment for continence health/bladder and bowel control in Australia. An overview of the key datasets that are used in this report are provided below.

National experience, awareness and attitudes survey (new data)

A national survey of 1,997 people, commissioned by the Continence Foundation of Australia and undertaken by SSI (now Dynata), assessed Australian's experience of incontinence, awareness of the condition and attitudes towards it. The survey was conducted using an online panel between 9 and 17 June 2017, distributed to a representative sample of Australians. Throughout the report this dataset is referred to as the National Survey.

Australian Institute of Health and Welfare (AIHW) and Australian Bureau of Statistics reports

The AIHW Report; 'Australia's Health 2016 (3.16 Incontinence)' provides an overview of what is known about the prevalence, risk factors and impacts of incontinence.

The ABS Report; 'Disability, Ageing and Carers, Australia: summary of findings' includes data on the prevalence of incontinence 2012.

CONTINENCE IN AUSTRALIA – THE DETAIL

Continence is the ability to have voluntary control over bladder and bowel functioning.

For most people, bladder and bowel control is established in childhood, however some people are born with incontinence and some develop it during their life.

Incontinence is a term that describes any accidental or involuntary loss of urine from the bladder (urinary incontinence) or bowel motion, faeces or wind from the bowel (faecal or bowel incontinence). The severity of incontinence can vary from 'leakage' through to complete loss of bladder and bowel control.

There are a range of factors that contribute to urinary incontinence including:ⁱ

- pregnancy and childbirth;
- constipation;
- prostate problems;
- impaired mobility;
- underlying musculoskeletal conditions (eg. arthritis);
- neurological disorders (eg. stroke, Parkinson disease, multiple sclerosis and spinal cord injuries);
- cognitive impairment (including dementia); and
- other health and lifestyle issues (eg. diabetes, cardiovascular disease, obesity, developmental disorders).

Factors that contribute to faecal incontinence are similar and urinary incontinence and urinary incontinence itself is associated with increased risk of faecal incontinence.ⁱⁱ

The experience of incontinence may affect emotional and psychological wellbeing, quality of life and ability to participate in normal activities of daily living.

Factors that contribute to urinary incontinence include:



Underlying musculoskeletal conditions (eg. arthritis)



Neurological disorders (eg. stroke, Parkinson disease, multiple sclerosis and spinal cord injuries); cognitive impairment (including dementia)



Other health and lifestyle issues (eg. diabetes, cardiovascular disease, obesity, developmental disorders)



Pregnancy and childbirth



Constipation



Prostate problems



Impaired mobility



74%
Almost three-quarters of people currently living with incontinence are women (74%).



Half
Half of all people with incontinence are aged between 40 and 59 years.

More than 1 in 3 Australians have experienced some form of incontinence.

A total of **38%** of Australians have experienced or currently experience incontinence. The National Survey found that 1 in 7 Australians (**14%**) reported currently experiencing incontinence, while a further **24%** reported having experienced some form of incontinence in the past.

Almost 1 in 3 Australians (**31%**) indicated that they can lose control of their bowel or bladder on occasion and **10%** indicate that they frequently lose control of their bladder or bowel.

Almost three-quarters of people currently living with incontinence are women (**74%**), with half of all people with incontinence are aged between 40 and 59 years.

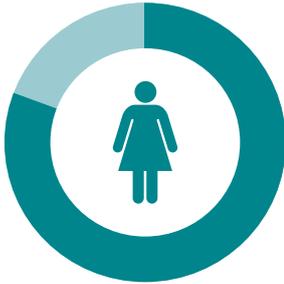
Women who have given birth, people with arthritis, men with prostate problems, people with mental health disorders, people living with disabilities and people with diabetes all demonstrated higher rates of incontinence than the general population.

Data from the AIHW indicates that people living permanently in residential aged care are also more likely to experience incontinence. In 2014, **81%** of women and **75%** of men in residential aged care experienced some degree of incontinence that wasn't self-managed.ⁱⁱⁱ Of these people, **71%** of women and **65%** of men experienced three or more episodes of incontinence each week.

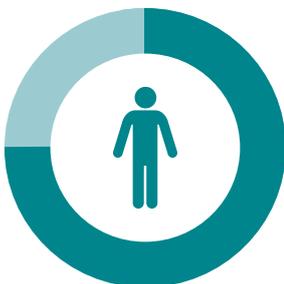
Prevalence of incontinence

	Currently experience incontinence (%)	Previous experience of incontinence (%)	Total (%)
Women who have given birth	27%	34%	61%
People with arthritis	27%	30%	57%
Men with prostate problems	27%	27%	54%
People with mental health disorders	23%	30%	53%
People with physical or intellectual disabilities	23%	24%	47%
People with diabetes	22%	24%	46%
General population	14%	24%	38%

IN 2014



81%
of women in residential aged care
experienced incontinence



75%
of men in residential aged care
experienced incontinence

Of these people, **71%** of women
and **65%** of men experienced
three or more episodes of
incontinence each week.

Data from the ABS indicates that approximately **1.8%** of Australians (or 391,000 people with disability) experienced severe incontinence in 2012. This was defined by 'the need for assistance with bladder or bowel control, and/or the use of continence aids'. This increased by **24%** (or 75,000 people) between 2009 and 2012.^{iv}

Incontinence impacts on people's social and emotional wellbeing and their ability to engage with the community.

The National Survey found that 39% of people who experience incontinence indicated that they are less confident in leaving the house, almost one-third (**32%**) indicate that it affects their mental health and wellbeing, one-quarter (**25%**) indicate that it affects their relationships with family and friends and just over 1 in 5 (**22%**) indicate that it affects their ability to go about their day to day activities.

There is strong stigma associated with incontinence.

Incontinence is deeply stigmatised.^v This is damaging to the overall psychosocial well-being of people who are experiencing incontinence and their carers.^{vi} This personal impact is influenced by cultural, social, and psychological factors along with concepts of self-image, self-worth, and health expectations.^{vii}

The National Survey found that over one-third (**34%**) of adult Australians would not discuss incontinence with their family or friends.

Individuals who suffer incontinence will go to great lengths to keep their condition a secret if they are able. They may be subjected to gossip, hostility, and other forms of social exclusion.^{viii} Stigmatization is a dimension of suffering added to the illness experience, and has been found to lead to social isolation, and delayed help-seeking.^{ix}

The stigma of incontinence and the taboos which surround it, combined with lack of knowledge and shame are powerful inhibitors of help-seeking even when people are suffering intensely from these conditions.^x

People often perceive some incontinence to be normal.

Incontinence is often perceived as a normal part of ageing and the result of child birth. The National Survey found that **63%** of people felt that some incontinence was inevitable following child birth and **48%** agreed that incontinence is an inevitable part of ageing. However, incontinence can be treated and managed, and in many cases, it can also be cured.

The stigma associated with incontinence and perception that incontinence is normal contributes to people not seeking help.

The National Survey found that a majority (**62%**) of Australians who currently experience incontinence or have experienced it in the past have not contacted a health professional regarding the issue. This is despite almost all Australians (**97%**) indicating that they would turn to a GP if they experienced incontinence. Men (**37.8%**) were more likely to contact a health professional regarding their incontinence than women (**29.1%**) who had contacted a health professional.

Australia's continence management program needs to continue into the future to meet future challenges.

Australia has a strong history of leadership and investment in the promotion of continence health and the management of incontinence. Between 1998 and 2010, the Australian Government supported the National Continence Management Strategy. Since 2010, the Australian Government has supported the prevention and management of incontinence through the initiatives: The National Continence Program (NCP) and the Continence Aids Payment Scheme (CAPS), which replaced the Continence Aids Assistance Scheme in 2010.



62%
of Australians who currently experience incontinence or have experienced it in the past have not contacted a health professional



37.8%
of men contacted a health professional



29.1%
of women contacted a health professional

AUSTRALIA'S CONTINENCE MANAGEMENT PROGRAM NEEDS TO CONTINUE TO MEET FUTURE CHALLENGES

The National Continence Program (NCP) supports activities, including:

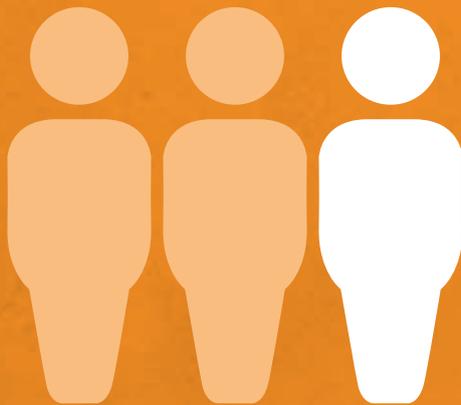
1. World Continence Week,
2. the National Conference on Incontinence (NCOI),
3. the National Continence Helpline,
4. the National Public Toilet Map,
5. the Bladder Bowel website,
6. awareness raising and prevention programs, and
7. education.

CAPS assists people with permanent and severe incontinence to meet some of the costs of their incontinence products.

These programs have made a difference to the lives of people with incontinence and have also contributed to vital awareness raising and prevention programs. This work needs to continue to meet future challenges, including disability and aged care sector reforms and changing demographics.

As the prevalence and costs associated with incontinence increase, and policy reforms such as the National Disability Insurance Scheme and Aged Care reforms are implemented, there is a need to ensure that people requiring support for incontinence and at the risk of incontinence, do not fall through the gaps.

A comprehensive approach to continence management needs to include prevention, early intervention, targeted work with at risk groups of people, workforce capacity building and improved data collection.



The National Survey found that **62%** of Australians who currently experience incontinence or have experienced it in the past have not contacted a health professional

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Continenence Foundation of Australia National Office

Suite 1, 407 Canterbury Road,
Surrey Hills, VIC 3127

National Continenence Helpline 1800 33 00 66

Telephone: 03 8692 8400

continenence.org.au