



Federal Election Platform 2022

March 2022

Incontinence is a health issue that impacts millions of Australians

Incontinence is a problem with bladder and/or bowel control, and it affects Australians from childhood to older age. It is a condition that stands alone or can be associated with a wide range of medical conditions, lifestyle and environmental factors.

Incontinence affects more than half of Australians.¹

80% of people living with incontinence in the community are women

50% of those living with incontinence stated that it affects their mental health

Incontinence can affect a person's physical, mental and emotional health, and it can also impact on a person's ability to engage with the community and in employment.

Inadequate diagnosis, treatment and support for incontinence is a significant health burden and cost to individuals and the health and social services budgets.

Recognition of the value and importance of continence health diagnosis, treatment and services, through specific and targeted investments, would contribute to better health for individuals and to better economic and social participation with the potential to reduce longer term health and social service costs.

Now is the time for action on continence care, support and prevention

The Foundation proposes the following as immediate priorities for policy action and investments in the next term of government:

1. National leadership to set the agenda for continence care and support through systemic change and evidenced based support and care

2. Increase the availability of specialist continence services and trained health professionals

3. Build the capability of the workforce across health, ageing and disability sectors to support people with incontinence.

“Services are stretched and there is poor use of available resources across the board. I’m particularly concerned about the lack of continence care and specialist services for regional and rural areas, especially for women and children and post-surgery. We need satellite clinics with Nurse Continence Specialists so we can better support people who are isolated and often unable to leave their homes because of their incontinence.”

Nurse Continence Specialist with over 25 years in community nursing, specialising in aged care.

Elicia's story – “Why didn't anyone tell me this could happen to me?”

Of all the changes a woman can face after giving birth, for Elicia, incontinence was the most challenging. Elicia was shocked when this happened to her and she felt completely unprepared.

“It wasn't until a physiotherapist gave me a brochure titled “One in three women who have ever had a baby wet themselves,” that I realised how common it is but I wondered why it wasn't something women or health professionals openly discussed.” she says

Eighteen months later, Elicia still experiences incontinence that impacts her day-to-day life and her ability to enjoy simple things like trips to the playground with her daughter, let alone any sustained or intensive

exercise. Whilst she accepts the road to recovery is long and not without bumps, incontinence is a hard thing for a young woman to deal with daily, particularly when it can occur randomly and without warning.

“I'd like to see the same level of awareness around birth injury and trauma as post-natal depression, so that women are provided with prior knowledge of the risk factors and likelihood of it happening, as well as how to deal with it,” says Elicia. “Women need to know where they can seek help and support and know that they are not alone.”

1

National leadership is needed for systemic change and evidenced based support and care

The National Continence Action Plan has not been updated since 2014.

Lack of policy focus and investment has resulted in:

- poor support for continence health in disability, health and aged care policy
- significant gaps in access to specialist continence services
- a lack of capability in the generalist health, aged care and disability support workforces
- increasing prevalence of incontinence, accompanied by increasing consumer and carer expectations of the availability and quality of continence care
- inadequate understanding about how to prevent or reduce the impact of incontinence
- data gaps limiting the profile of continence health.

The Foundation urges the development and commitment to a National Continence Action Plan that provides:

- improved access to specialist continence care
- workforce capacity building,
- standards for safe, quality continence care
- prevention and early intervention from childhood across the life course
- increased social and economic participation by reducing barriers for consumers and carers
- improved research and data collection.

“Incontinence has traditionally been viewed as an older woman’s problem, but this group certainly don’t make up most of my clients. I am now seeing much younger women, some soon after childbirth, as well as women in their 40s and 50s. Many of these women have reduced their engagement in exercise and other enjoyable activities and have withdrawn from life physically, emotionally, socially, and sexually. I want the message to be clearer for women that these issues shouldn’t hold you back from having a good sex life, being active, playing with your kids and doing the things you enjoy.”

Specialist Women’s, Men’s & Pelvic Health Physiotherapist

2

Increase the availability of specialist continence services and trained health professionals

There are insufficient specialist continence services and qualified staff to meet current and increasing demand, including in rural and regional areas with additional support of much needed sub-specialist support heavily centred in major metropolitan regions across Australia for example paediatrics, women's health and surgical intervention. In addition to a reduction in the number of specialist services, there has been a loss of recognition of the importance of the skills and expertise of Specialist Continence Nurses.

We estimate that approximately one Nurse Continence Specialist per **2,500** people with faecal incontinence and approximately one per **5,000** people with urinary incontinence is required.^{14,15}

Incontinence is common, and if left untreated becomes a chronic health condition. However, with specialist support causes can still be treatable and at the very least be better managed. Specialist services and qualified health professionals can support individuals and families to

- Improve their continence
- Manage their related conditions
- Improve wellbeing and participation in the community and workforce

The Foundation proposes the following priorities for policy action and investment

- Funding of additional Nurse Continence Specialist positions, through local health networks, and embedding them in multi-disciplinary teams in health and community-based settings, particularly in rural and regional areas
- Development and implementation of a strategy to increase the Nurse Continence Specialist and pelvic health Physiotherapist workforce to support expansion of services can be expanded and meet increasing demand
- Increased funding to the National Continence Helpline to build on existing capabilities to deliver additional clinical support and develop a model of care to support better health seeking behaviours
- Development of higher education career opportunities for continence specialisation to support the increasing need of the community across the lifespan

Community Stories

Betty's story - The benefits of good continence care and support

The Aged Care Royal Commission highlighted the standards necessary to ensure good continence care. Betty's experience illustrates how good management of her incontinence in residential aged care can improve the resident's experience. After a lengthy hospitalisation, Betty, 87, recently moved into residential aged care as her care needs, including continence, were no longer able to be managed at home. Betty says the care and understanding of the staff have helped her deal with her incontinence with dignity.

"I was very embarrassed at first, to have to ask them to help me change, but they were so lovely. I remember one said to me – it is hard to accept help, but it is my job to support you to feel clean and comfortable. You can talk with me about your personal care, and I will only tell other people if it helps them care for you too."

Betty's family are also relieved to know that she has good care, and that staff can be responsive to her changing needs. Betty is currently on a Restorative Continence Care Plan where she can self-manage with support.

Lily's* story

"Incontinence is associated with older people; however, it affects so many children. It is important to talk about it and remove the stigma. Let's learn to talk about incontinence like we now do periods."

This is the message from the mother of Lily*, a five-year-old who was born with the congenital condition Imperforate Anus/Anorectal Malformation (IA/ARM). As a result, Lily has continence issues and will need to manage this long term. Her continence is managed using continence aids, diet, staying healthy and carefully scheduling her life around her toileting needs.

Hailing from a regional area, the family had to travel to the city for Lily to have extensive surgeries to help her be socially continent. She will require further surgeries in the future. IA/ARM takes a lot of time to manage and Lily's* mother advises finding community and support as soon as possible is critical to your child's wellbeing as well as your own.

"If something doesn't feel right don't be afraid to ask questions, no-one knows your child better than you."

***Name has been changed to protect individual privacy**

3

Build the capability of the workforce across health, ageing and disability sectors to support people with incontinence

Adequate education and training to deliver safe and effective continence care and management is essential.

Currently, primary health care professionals and people working with populations at high risk of incontinence, including doctors, nurses, midwives, and personal care workers have been shown to be inadequately prepared in their training to provide effective continence-related care.⁵⁻⁸

Concerns have been raised with the Foundation about a loss of specialist continence education and training programs in conjunction with the erosion of the teaching and assessment of continence capabilities in generic healthcare training.

Improved frontline workforce capacity will directly:

- improve the quality of life of people living with incontinence
- reduce preventable health complications and unnecessary hospitalisations
- delay entry to residential aged care.

The Foundation proposes the following priorities for policy action and investment

- Continence modules mandated in workforce training and professional development, and support for CPD accreditation be put in place to ensure consistent standards are met.
- Include compulsory continence education in undergraduate courses for all relevant health professions.
- Mandate competency units in continence care in Certificate III in Individual Support, Certificate IV in Ageing Support and Certificate IV in Disability qualifications.
- Comprehensive standards for continence care and services are introduced for private and public health services, supported accommodation, residential aged care, home care, and disability support.

Alan's Story – The Prostate Cancer Journey

After two bouts of prostate cancer, Alan required surgery for the removal of his prostate gland, from which he needed to recover both physically and emotionally. That included having to deal with wearing pull-up pads to handle the incontinence. "I felt like a baby wearing them", he says. During the first 12-months following the operation, Alan's bladder and bowel also took time to heal.

"Some days I could go for a few hours before having to take a leak, but then there would be days where I was going every half an hour. I found this

emotionally draining to the point of one day sitting on the toilet and crying. I had had enough of this incontinence and leaking and it was really getting to me," says Alan.

Dealing with incontinence after prostate surgery often comes as a complete shock for many men.

Alan was able to access support from a physiotherapist who was able to help him slowly get himself back on track. "Despite having to deal with the occasional leak, 11 years later my continence has improved and I feel more confident in my day-to-day activities," says Alan.

The Impact of Incontinence

- By 2030, more than

6.2 million

Australians will be living with incontinence.¹

- Productivity losses of people with incontinence are estimated to be

\$34 billion

per year due to lower-than-average employment rates of people experiencing incontinence.¹

- Without action, the number of people in residential aged care living with incontinence is expected to almost double, from 129,000 in 2010 to more than

250,000

in 2030.¹

The Impact of Incontinence

Incontinence impacts people of all ages and genders

- **80%** of people in the community with urinary incontinence are women.¹
- **46%** of people who experience incontinence are under the age of 50 years.¹
- **19%** of children starting primary school are estimated to have incontinence.² Many children with some form of incontinence at this age continue to have incontinence into adolescence and adulthood.^{3,4}

Incontinence impact wellbeing, inclusion and economic participation

- Lived experience of incontinence is different for every person. It has significant impacts on the health, well-being, inclusion and social and economic participation of individuals and families and on our communities.
- Incontinence can have a significant impact on workforce participation, including on concentration, performance of physical activities, self-confidence, and ability to complete tasks without interruption. The impact increases according to the severity and level of assistance required to manage incontinence.⁹
- Workforce participation for people aged 15–64 who always or sometimes need assistance with managing bladder or bowel control is only **20%**. For people who have difficulty but do not need assistance the rate is still only **42%**.¹⁰
- People experiencing faecal incontinence find the workplace is the most complicated situation to manage when outside the home.¹¹
- A National Survey undertaken by the Continence Foundation found that incontinence is having significant impacts on health and wellbeing, with half (50 per cent) of those living with incontinence stated that it affects their mental health, and **52** per cent stated it causes them to be less confident when leaving the house.¹²

About the Continenence Foundation of Australia

The Continenence Foundation of Australia is the peak not-for-profit organisation for people with incontinence, their families and carers and the health professionals supporting them.

Our vision is an Australian community free of the stigma and restrictions of all aspects of incontinence across the lifespan.

The Foundation works with people of all ages impacted by incontinence, government and other stakeholders to provide support services, education and information aimed at reducing the stigma and restrictions of incontinence.

The Foundation has managed the National Continenence Helpline since 1999. The Helpline is a free, confidential information and advice line for people affected by incontinence or bladder and bowel issues, staffed by Nurse Continenence Specialists.

In the past financial year, we responded to more than **21,000** calls (carers **34%**, consumers **44%**, providers **22%**).

Other key activities of the Foundation include:

- Managing the National Public Toilet Map since 2020. Visits to the map have increased from approximately **700,000** visits to more than **2 million** per annum in that timeframe.
- Producing more than **554** YouTube continence videos with over **6,500** subscribers. The videos range from 3D animations of pelvic floors to animated videos in **10** different languages.
- Maintaining an online service directory of more than **800** continence services across Australia. The directory can be searched by postcode to find the nearest service.
- Publishing hundreds of articles on our website for service providers and consumers that cover all areas from toilet accessibility to continence products.

Providing education and support to health professionals:

The Foundation has developed and runs a number of on-line education programs and webinars.

In the six months from July to December 2021 there were **2,359** enrolments to these programs.

The professions registering for the programs in this period include:

- Enrolled Nurse
- Medical Specialist
- Nurse Continenence Specialist
- General Practitioner
- Physiotherapist
- Registered Nurse
- Medical or nursing student
- Consumers

The **Continenence Support Now** website provides free access to continence support for community workers. It attracted over **4,500** individual users in the 6 months from July 2021.

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