



Continence
Foundation
of Australia

**Federal
Pre-Budget
Submission
2022-2023**



About the Continenace Foundation Of Australia

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

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 Continenace 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 Continenace 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 health professional education:

- o Aspects of Continenace Care
- o Essentials of Continenace
- o Pelvic Floor Fitness
- o eContinenace Paediatrics course
- o Continenace SMART Care (residential aged care)

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Priorities to tackle incontinence

The 2022-23 Budget presents an opportunity for government and decision-makers to provide improved support and access to evidence-based continence care and services through planned improvements and investments to the health, disability and aged care sectors.

The Continenace Foundation of Australia recommends four priorities:

- Increase access to continence support
- Build a capable workforce to support people with incontinence
- Improve economic participation
- Accelerate research and evidence-based data

We have an opportunity to take action to deliver a better health system today, and for generations to come.

This can be achieved with an investment of \$20 million across three years.

The Impact Of Incontinence On 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.

^ **One in four** Australians is affected by incontinence.¹

^ By 2030, more than **6.2 million** Australians will be living with incontinence.¹

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

^ Productivity losses of people with incontinence were estimated by Deloitte Access Economics to be **\$34.1 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

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}

A National Continenace Action Plan is Urgently Needed

There is currently no integrated response to incontinence, to support and improve continence care and management. An integrated approach can significantly improve quality of life and deliver substantial cost savings to individuals and governments.

The last National Continenace Action Plan (NCAP) was for the period 2011-14.⁵ The achievements of the NCAP include the National Continenace Program (NCP), Continenace Aids Payment Scheme (CAPS) and the Stoma Appliance Scheme. These programs and initiatives have made a difference to the lives of Australians living with incontinence and contributed to vital awareness raising and prevention programs. This work must continue to meet future challenges, including urgent aged care sector reforms arising from the Aged Care Royal Commission and changing demographics.

The relationship of existing programs to recent policy initiatives including the National Disability Insurance Scheme (NDIS) and aged care reforms remains unclear, with both consumers and service providers navigating a shifting landscape of eligibility and funding requirements.

The Continenace Foundation of Australia calls on the Commonwealth Government to address this lack of an integrated policy response in the next term of government, with the development of a new National Continenace Action Plan.

Alongside this commitment, investment in the 2022-23 Budget to increase and improve existing services, build the workforce to effectively assess, treat and manage incontinence, and therefore respond more effectively to the needs of people with incontinence, is needed. This investment will result in improved health outcomes, quality of life and economic participation of people experiencing incontinence.

Priority 1: Increase Access To Continence Support

The problem

- ^ Incontinence is a common condition that can be treated and proactively managed, however **70%** of people with urinary incontinence do not seek advice and treatment.^{6,7}
- ^ There are insufficient specialist continence services and qualified staff to meet existing demand.
- ^ Access to comprehensive continence assessments and ongoing continence management and care services varies substantially according to:
 - geographic location,
 - availability of qualified health professionals and public health continence services, and
 - whether a consumer is eligible for an individualised funding scheme.

Recommended actions:

- Campaign to increase awareness of incontinence and strategies to reduce its impact across all ages and stages of life
- Increase funding to the National Continence Helpline to support the needs of consumers and their carers, and health professionals who do not have access to continence clinicians
- Develop a national longitudinal survey of continence-related issues, inclusive of rural and remote regions, to better understand prevalence of incontinence, demand and facilitate access to relevant health professionals including Nurse Continence Specialists and Pelvic Floor Physiotherapists.

Investment: \$5 million over 3 years

Priority 2: Build A Capable Workforce To Support People With Incontinence

The problem

- ^ Currently, primary health care professionals and people working with populations at high risk of incontinence, including doctors, nurses, midwives, and personal care workers have all been shown to be inadequately prepared in their education and/or training to provide quality and effective continence-related care.⁸⁻¹¹
- ^ Inadequate frontline workforce capacity and knowledge directly reduces the opportunities for treatment or management of incontinence, impacting the quality of life of people living with incontinence, increases preventable health complications and unnecessary hospitalisations, and results in earlier entry to residential aged care.
- ^ Insufficient specialist continence services and qualified staff to meet demand. 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 based on UK studies.^{12,13}
- ^ The existing arrangements under the NDIS significantly undervalue the qualifications and skills of Nurse Continence Specialists. This increases the risk of specialist continence practitioners withdrawing as NDIS providers and therefore decreasing access to high quality care for people with disability.
- ^ There has been a loss of specialist continence education and training programs in conjunction with erosion of the teaching and assessment of continence capabilities in generic healthcare training.

Recommended actions:

- Develop a curriculum standard for a unit of study on continence assessment, management, prevention, and care in all undergraduate nurse training courses (diploma and degree level)
- Mandate a unit of competency in continence care in the Certificate III in Individual Support, Certificate IV in Ageing Support and Certificate IV in Disability qualifications
- Develop Continence Standards for the provision of specialist continence care and services in all private and public health services, supported accommodation, residential aged care, home care, and disability support.
- Expand access to online courses for health professionals, including:
 - **Aspects of Continence Care**
 - **Essentials of Continence**
 - **Pelvic Floor Fitness**
 - **eContinence Paediatrics course**

Investment: \$3 million over 3 years

Priority 3: Improve Economic Participation

The problem

- ^ 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.¹⁴
- ^ 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%**.¹⁵
- ^ People experiencing faecal incontinence find the workplace is the most complicated situation to manage when outside the home.¹⁶
- ^ Productivity losses relative to incontinence are estimated at approximately **\$34.1 billion** due to lower employment rates.¹

Recommended actions:

- Develop workplace continence standards and guidelines in consultation with the health and disability sector to remove the workplace as a barrier to managing incontinence
- Develop a toolkit and resources for employers to establish workplace facilities and practices that support employees experiencing incontinence.
- Provide specialist information and advice to support people experiencing incontinence to stay in the workforce or return to employment.

Investment: \$2 million over 3 years

Priority 4: Accelerate Research And Data Evidence-base

The problem

- ^ There are significant data and research gaps that still exist in our knowledge about bladder and bowel control issues.
- ^ There are inconsistencies and lower priority on reporting on incontinence across different sectors.
- ^ Lack of focus on incontinence as a human rights issue needing urgent government attention.

The Australian Government must address the failure of the market to invest in research and development in relation to incontinence which has severe individual and societal consequences.

Recommended actions:

- Inclusion of incontinence as a priority for chronic disease research funding
- Comprehensive continence health prevention and management research to address gaps in translation of research into practice
- Update research of the prevalence and costs of incontinence for the Australian population
- Regular updates of prevalence data and activity data through existing national longitudinal surveys to provide accurate measures of demand for continence health services
- Develop a national longitudinal survey, inclusive of continence-related measures, to enable efficient and effective policy and practitioner responses.
- Conduct service mapping of existing continence specialist services nationally to understand services offered, access to and service gaps, funding issues and interface with the health, aged care, and disability sectors.

Investment: \$10 million over 3 years

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