



**Continenence
Foundation
of Australia**

2023 – 2024
Policy and
Pre-Budget
Submission

About the Continenace Foundation of Australia

The Continenace Foundation of Australia is the national peak, non-profit organisation for people with incontinence and their families, carers and the health professionals supporting them.

The Foundation works with people of all ages impacted by incontinence, as well as government and other stakeholders to provide support services, education, advocacy, community awareness and information aimed at reducing the stigma and restrictions of incontinence. The Foundation's Vision is 'an Australian community free of the stigma and restrictions of all aspects of incontinence across the lifespan'.

The Continenace Foundation of Australia is the primary source of continence information for millions of people each year. In 2022, the www.continenace.org.au website had 2.3 million pageviews and since 2019, the foundation has distributed over 1.6 million clinical collaterals.

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/or bowel issues and is staffed by Nurse Continenace Specialists. In the last financial year, we responded to over 21,000 calls (carers 34%, consumers 42%, providers 22%). 97% of consumers and professionals were satisfied with their call and 96% stated their questions and challenges were completely understood.

Major activities of the Foundation include

- Managing the National Public Toilet Map since 2000. To date, visits to the map have increased by 65% and app downloads have increased by 244%. Toilet map searches have increased by over a million since 2000 and there were over 3 million searches for public toilets over the past 12 months
- Producing more than 486 You Tube continence videos with over 7,891 subscribers. The videos range from 3D animations of pelvic floor anatomy to animated videos in 11 languages

- Maintaining an online service directory of more than 880 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.

The Impact

Incontinence is a problem with bladder and/or bowel health 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 currently affects one in four Australian adults and the total number of Australians aged over 15 years with incontinence is projected to grow from 5.1 million in 2021 to 6.2 million by 2030¹. Incontinence is recognised as a disability under the Disability Discrimination Act 1992, often co-occurs with other chronic diseases and is a condition that would benefit from a Chronic Disease Management Plan.

Incontinence is embarrassing, highly stigmatised and dramatically increases social isolation². Recent surveys show that more than 70% of people living with incontinence do not seek treatment³.

Incontinence is one of the three critical factors contributing to older Australians needing to move from home-based-care to residential aged care⁴.

Productivity losses arising from incontinence were estimated to be approximately \$34.1 billion in 2010 due to lower than average employment rates of those with incontinence¹.

Economic Impact

The Deloitte Access Economic report on the economic impact of incontinence in 2010 found that the total financial cost of incontinence was estimated to be \$43 billion at that time, or approximately \$9,014 per person with incontinence.

Total health system expenditure on incontinence in the Australian population was estimated at \$271 million or \$57 per person with incontinence.

Productivity losses of those with incontinence were estimated to be approximately \$34.1 billion in 2010 due to lower than average employment rates of those with incontinence.

Australian Labor Governments have been world leaders in responding to continence health, with the introduction of the National Continence Helpline, continence product subsidies and development of professional development programs for health workers. However, despite increasing prevalence of incontinence in the population, there has been no updated Australian Continence Action Plan since 2014.

As a prevalent and pervasive stigmatised health condition that has substantial impact on the health and wellbeing of individuals and contributes significantly to the burden of demand for health care of management of complex care needs, chronic health conditions and for the ageing population, incontinence has been neglected in health policy and persistently underfunded when compared to need and cost impacts. For the Australian Government to achieve its overall objective to improve the health and wellbeing of Australians and particularly of vulnerable and disadvantaged groups within the Australian population, incontinence requires a proactive targeted program of additional support and capability.

What we know

- Over half of women and more than one in three men living in the community with incontinence are under 50 years of age¹
- One in three Australians with a disability currently experience incontinence⁵
- Over 75% of residential aged care consumers experience incontinence, with most at higher severity levels⁶
- People with other chronic conditions including cancer, diabetes, asthma, heart/cardiovascular disease and constipation are all at higher risk of incontinence¹.

Urinary incontinence is associated with a significantly greater risk of falls, longer periods of hospitalisation and higher mortality rates in older people receiving home care services^{7,8}. These examples highlight the growing continence needs of the population and are indicative of the need to provide appropriate primary health care earlier to reduce costs associated with incontinence.

The stigmatisation and personal shame associated with incontinence can mean that appropriate care is not requested in primary care and is often not offered, adding to the social and health burden of this condition. Incontinence is well known to affect mental health and quality of life and may lead to withdrawal from social contact, physical activity and work⁹.

Framework for the Future of Continence Care

Australia requires a purposeful, evidence-based approach to improve the treatment and management of all forms of incontinence and to promote continence health for people at higher risk of incontinence. Lack of health care attention, together with societal and individual stigma cannot continue.

The Continence Foundation of Australia is a unique Australian continence organisation providing expert consumer support, education and support for health professionals and services. The Foundation has worked with, and been managed by, leading continence health experts across the medical, nursing, physiotherapy and other allied health sectors, and has built and is continuing to progress strong consumer leadership within the organisation. The Foundation provides this policy and budget submission based on the organisation's long-established leading expertise and knowledge of the burden of poorly recognised, treated and managed incontinence on individuals, families and the health and aged care systems.

The Foundation proposes two investment initiatives that would immediately improve the continence health structure, awareness, knowledge and treatment for individuals and support the Government's commitment to improve primary health care for all Australians and improve prevention and management of ongoing and chronic conditions¹⁰.

We are confident that investment in these two initiatives will advance and improve access to preventive care and enhance outcomes for people at risk of, and/or experiencing incontinence.

1. Initiative 1: Develop an Australian Continence Action Plan

- Build on the advancements made in continence care and services, providing national leadership in incontinence prevention and reduce the prevalence of incontinence
- Improve understanding and awareness of individual risk factors throughout the lifespan and empower behaviour change to improve quality of life
- Reduce the inequities of access of continence services and improve access to comprehensive continence management and care

- Progress the objectives of the National Continence Program, and existing activities, to raise awareness, address stigma and discrimination, and provide information and training.
2. Initiative 2: Implement a capability building program for general practice to strengthen the capacity of primary health care to meet increasing continence care needs throughout the population
- Investment in a scalable capability building program for general practice strengthening the principles of primary health care to meet the increasing continence needs of populations at risk, those with complex care requirements and for people over the age of 65 years living at home or in residential care
 - Support the role of primary care providers to identify and investigate the incidence of incontinence early and use referral services appropriately
 - Increase awareness of the importance of health promotion and embed utilisation of optimal continence care pathways
 - Implementation of evidence based, best practice care using a quality continence care standard and model of continence care to support the ageing population.

Initiative 1: Develop an Australian Continence Action Plan

The problem

The National Continence Program Action Plan for 2011-14¹¹, recognised that incontinence is a significant health issue that has physical, social and economic implications for women and men of all ages, as well as children, carers, families and the community.

The National Continence Program Action Plan was not renewed, resulting in a fragmented and reactive approach to need and service provision with no national policy framework to monitor requirements, guide service development and make best use of health care capacity and resources to reduce the preventable impact of this widely prevalent and debilitating health condition.

The case for investment

The burden of disease of incontinence was estimated to cost \$23.8 billion in 2010. This was attributed to the impact of an estimated 140,108 Disability Adjusted Life Years¹ caused by incontinence in the population at that time. This estimate will have increased with population increase and ageing since then.

Despite the impact of incontinence, at all ages, on the health of individuals and families on the health and aged care systems and the Australian population, primary health care policy and service provision in Australia has not recognised incontinence as a significant health issue. The RACGP identifies urinary incontinence as an issue requiring identification in the population at higher risk and that incontinence affects more than one in three women (37%), almost one-fifth of children (19%) and 13% of men. The RACGP *Red Book* which provides guidelines to preventive activities in general practice, states that

Of those sitting in a GP waiting room, 65% of women and 30% of men report some type of urinary incontinence, yet only 31% of these people report having sought help from a health professional. Primary care professionals are in a position to take a more proactive

approach to incontinence treatment by asking about urinary symptoms in at-risk groups during routine appointments. There remains considerable health decrement due to urinary incontinence in those not receiving help in a population readily accessible to primary care services.

Tellingly, the *Red Book* provides advice to general practitioners that the Continence Foundation of Australia provides a helpline for consumers and healthcare professionals and provides ‘many evidence-based resources’ for consumers. The guidelines for general practitioners advise on screening tools to assess individuals at risk of incontinence.

Despite the RACGP advice, it is evident that the low rates of consumer requests for health care and the low rates of identification of people with incontinence have not improved over time.

Barriers to accessing continence care are significantly compounded for people from culturally and linguistically diverse backgrounds, as well as facing multiple other barriers, including difficulty navigating the health system, lack of access to interpreters, costs of care and prior experiences.

A new Australian Continence Action Plan would continue the Labor Government’s commitment to this health issue and contribute to the Government’s commitment to strengthening Medicare and to improving aged care and disability services.

Improving community and health professional awareness, knowledge and understanding of incontinence is essential to reduce the stigma surrounding incontinence, the personal discourse and the reluctance of services to initiate continence support. It is also crucial to promote and support self-care and self-management of continence health across the life course.

The Australian Continence Action Plan should establish national continence care priorities and action areas over the next ten years and


- Provide a comprehensive approach to continence management including prevention, early intervention, targeted work with at risk groups of people, workforce capacity building and improved data collection
- Outline national strategic objectives, ambitions, goals and priority actions for continence management

- Ensure that policies and programs are informed by the best evidence and address the needs of the millions of Australians living with incontinence
- Provide a coordinated proactive approach to existing plans and strategies that focus on at-risk population groups, such as the National Women's and Men's Health Strategies.

The Australian Continence Action Plan should be developed through

- Defining terms of reference
- Establishing an expert advisory group, with terms of reference and with full representation from the broad group of stakeholders who will support the delivery of the support plan
- Wide consultation with consumers, health professionals across disciplines, service providers, funders, scientists and academics
 - to identify the enablers to support action in the Australian health system
 - identify the key priorities to deliver a multidisciplinary approach to continence care
- Review of international best practice
- Identification of a future research agenda required to support best practice evidence-based care and service delivery
- Circulation of a draft plan for broad consultation nationally
- Capacity building supports for primary health care workers, to be able to appropriately screen, identify, support and make referrals for people experiencing symptoms such as urgency, frequency, constipation and nocturia, as well as urinary and faecal incontinence.

The Continence Foundation of Australia is positioned to provide the leadership, support and management of the development of the Australian Continence Action Plan.

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Budget: \$1.2 million over two years

Initiative 2: Implement a Capability Building Program for General Practice

The problem

Primary health care professionals and people working with populations at high risk of incontinence (including doctors, nurses, midwives and personal care workers) are not adequately prepared in their education and training to provide quality and effective continence-related care. This lack of capability in primary health care provision means continence-related care is often neglected to the detriment of consumers and carers.

Talking about incontinence can be difficult, but sensitive enquiry from a health professional can help. Two Australian studies reported that 70% of people with urinary incontinence do not seek advice and treatment for their problem^{3,12}. Faecal incontinence is even less likely to be raised as an issue by either the consumer or health professional.

The final report of the Royal Commission into Aged Care Quality and Safety highlighted that current continence care and management practices are failing the Australian community, especially the most vulnerable people in our community. For older people, the consequences of unsafe and ineffective continence care and management can lead to life-changing health impacts^{13,14,15}.

The Foundation offers advice and information in the form of a variety of continence resources and services suitable for health workers across a range of roles. Feedback from General Practitioners who had engaged with the Foundation's National Continence Helpline reported more than 60% were very or extremely satisfied with the experience, highlighting how access to phone consultation with a Nurse Continence Specialist provides opportunities¹⁶.

Continence is a health condition capable of early recognition, potentially preventable and always manageable. What general practices are lacking is the immediate and responsive access to continence information and best practice continence health pathways across systems and services to meet the needs of the consumer and provide desired quality outcomes.

Best practice

Studies into collaborative teams-based care have shown that not only did this model result in better quality of life and effective management of incontinence for consumers but health professionals who worked with the Nurse Continence Specialists said they played a strong role in referrals, case management participation and outcome focused care planning. A high level of interdisciplinary collaboration and teamwork was identified between the Nurse Continence Specialist and the rest of the team including community nurses, allied health and medical practitioners¹⁷.

The case for investment

Prevention of illness is the key to Australia's future health, both individually and collectively. Approximately 32% of Australia's total burden of disease can be attributed to modifiable risk factors¹⁸.

Preventive healthcare is an important activity in general practice which includes the prevention of illness, the early detection of specific disease, and the promotion and maintenance of health. Preventive health care can also play an integral and critical role in addressing the health disparities faced by disadvantaged and vulnerable population groups¹⁸.

This initiative proposes to develop and drive a change to impediments of the existing health care structure and delivery in general practice, enabling and promoting better outcomes for people at risk of and/or experiencing bladder and/or bowel control health issues through the implementation of a scalable pilot project to build capability in general practice.

The Continenace Foundation of Australia recommends the establishment of a targeted Nurse Continence Specialist (NCS) workforce to support up to six Primary Health Networks over three years. The NCS's scope of practice encompasses knowledge and advanced practice skills in continence care, will support and capacity build general practices in the Primary Health Network region, becoming an integral part of an interdisciplinary approach to care of people who have incontinence and other bladder, bowel and/or pelvic floor muscle dysfunction¹⁹.

The NCS workforce will build up responsive continence health pathways across systems and services in local Primary Health Network regions, which supports improving the efficiency and effectiveness of health services for people, particularly those at risk of poor health outcomes and improving the coordination of health services and increasing access and quality support for people²⁰.

While the Continence Foundation of Australia will lead and manage the program through fund management, expert training and resource support to the NCS workforce, the Primary Health Networks are best placed to support this program, sharing their expertise and knowledge to connect the NCS and coordinate the services to deliver on the objectives of the program to the community.

Recommended activities include

1. A phased implementation over three years and evaluation of a continence capability program for general practice and aged care at six Primary Health Networks.
2. Each Primary Health Network would be funded to provide two full time equivalent Nurse Continence Specialists, who would support general practice and aged care to
 - Identify incontinence
 - Treat incontinence
 - Refer for additional support.
3. As an extension of the primary health care role, general practice teams would take a proactive approach to
 - Identify those who are experiencing incontinence and those populations at risk
 - Identify risk and manage initial impact of incontinence including reversible causes
 - Refer consumers for appropriate specialist continence services.
4. Improved workforce capability in the primary health system will directly improve the quality of life for people living with incontinence in the community and residential aged care. With specialist support, incontinence can be treated and at the very least be better managed.

The Continence Foundation of Australia would be responsible for developing the program and working with commissioned services to ensure fidelity to the model.

An integrated participatory evaluation of the program will occur to assess the effectiveness or impact of the program and process or plan throughout the implementation. At the end of the three years, the program's recommendation will be to scale up and be extended to all Primary Health Networks in Australia.

Incontinence is not something people talk about. 78% of Australians have never discussed incontinence with their GP or family doctor. 56% who currently or previously experienced incontinence have not contacted a health professional.

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Budget: \$5.1 million over three years

Contact details:

Rowan Cockerell

Chief Executive Officer

1/407 Canterbury Rd, Surrey Hills, VIC 3127 P +61 3 8692 8400 E info@continence.org.au

Consumer stories

“I’m forever on the alert; it’s a continual stress. Life and work are constantly distracted and compromised”.

Ian

“An older gentleman who recently called the Continence Helpline said he had been living with incontinence for 10 years without realising there was help and support so readily available”.

NCHL Nurse Continence Specialist

“Apart from the emotional toll, there’s the financial burden, and I’m not eligible for funding to help manage the costs of all the continence products, laundry, laxatives, UTI medication, medical appointments, and other expenses”.

Mother of adult child with faecal 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”.

Nurse Continence Specialist with over 25 years in community nursing

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”.

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

Steph kept working for as long as she could but eventually had to make a tough decision. “The result was I had to medically retire myself from my career, because there was no choice, no support, no help”.

Bridge, Summer 2023

Unable to make it from the lounge to ensuite without having an accident, Leanne couldn’t leave the house, go to the shops, or visit the office. She was completely housebound and isolated”.

Bridge, Summer 2023

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