



Continenace Foundation of Australia Pre-Budget Submission 2021-2022

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AUSTRALIA NEEDS ACTION ON INCONTINENCE

Time for a new National approach.



Annual costs exceed \$67 billion.



1 in 4 Australians experience incontinence and many more are impacted by caring for someone with incontinence.



Labour force participation by people with severe incontinence is less than half that of people without severe incontinence

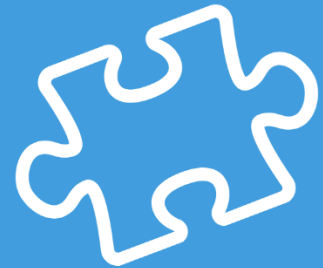


By 2030 over 6.2 million Australians will be affected by incontinence.

A NEW STRATEGY ON INCONTINENCE

A comprehensive approach to incontinence must include:

- Prevention and early detection
- Support for economic participation by people living with incontinence
- Standards for safe, quality continence care
- Workforce capacity building, and
- Improved data collection.



\$7 MILLION OVER 5 YEARS WILL DELIVER THE STRATEGY



National Awareness campaign to reduce stigma and get Australians talking about incontinence



National Economic Participation plan - for people affected by incontinence so they can return to the workforce



National Workforce Capacity Building plan - getting specialist care to those who need it



National Research Agenda - finding the answers to prevention, care and diverse needs



Contenance Foundation of Australia Pre-budget submission 2021-2022

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AUSTRALIA NEEDS ACTION ON INCONTINENCE: Time for a new national approach

Executive summary

Incontinence is one of the commonest health conditions, affecting one in four Australians with annual costs exceeding \$67 billion. With increasing prevalence, by 2030 over 6.2 million Australians will be affected by incontinence. The Continence Foundation of Australia calls for urgent action to increase access to preventive health care, reducing the burden of disease and costs to government.

Actions arising from the former National Continence Management Strategy made a difference to the lives of Australians living with or at risk of incontinence and contributed to vital awareness raising and prevention programs. The Foundation has delivered programs under the National Continence Program for over a decade.

However, there is currently no commitment to funding beyond 30 June 2021. This submission seeks to sustain current investment by the Australian Government and extend those investments to address the substantial barriers contributing to direct and indirect health expenditure. To meet future demographic challenges and urgent sector reforms arising from Royal Commissions, a comprehensive approach to incontinence must include:

- prevention and early intervention
- support for economic participation by people living with incontinence
- standards for safe, quality continence care
- workforce capacity building, and
- improved data collection.

Immediate Action: A 5-year National Strategy on Incontinence

To address the immediate needs of people living with or at risk of incontinence and gaps in data on prevalence and costs, additional funding for a 5-year National Strategy on Incontinence is required in 2021. A National Strategy on Incontinence funded in the 2021-22 budget, will provide a roadmap to address identified objectives and priorities.

The Strategy would include:

- 1. National Awareness Campaign: \$1 million over 5 years**
- 2. National Workforce Capacity Building Plan: \$0.5 million over 5 years**
- 3. National Economic Participation Plan: \$0.5 million over 5 years**
- 4. National Research Agenda: \$5 million over 5 years**

In the past, Australia has been a leader in continence health promotion and management. A National Strategy will ensure that this situation can continue. The Foundation has the expertise and capacity to develop the Strategy in partnership with the Australian Government.

Increasing prevalence and associated costs of incontinence impacts across health, aged care and disability services. Government investment now will improve quality of life for individuals and families and reduce costs to government in the future.

The Continence Foundation of Australia looks forward to working with the Australian Government to deliver improved health outcomes for all Australians.

About the Continence Foundation of Australia

The Continence Foundation of Australia is a not-for-profit organisation and the national peak body promoting bladder, bowel and pelvic floor health. Our vision is an Australian community free of the stigma and restrictions of incontinence.

The Continence Foundation of Australia exists to serve all Australians as the peak body for incontinence prevention, management, education, awareness, information and advocacy. With representation in each state and territory, we provide information, support and resources for individuals, carers and health professionals.

The mission of the Continence Foundation of Australia is to represent the interests of all Australians affected by, or at risk of, bladder and bowel control problems and pelvic floor muscle dysfunction.

About this submission

This submission seeks to sustain current investment by the Australian Government in continence services and supports and extend those investments to address the substantial barriers contributing to direct and indirect health expenditure. This investment must aim to improve prevention and management of incontinence and reduce the impact in the Australian population, particularly for older people and people with disability. The Continence Foundation of Australia proposes additional funding of \$7 million over 5 years by the Australian Government to implement a comprehensive National Strategy on Incontinence commencing in 2021.

Incontinence facts and stats

National impacts of incontinence

- Over 5 million Australians – 1 in 4 people aged 15 years or over – experience bladder or bowel control problems ¹
- 80% of people with urinary incontinence are women ¹
- A quarter of people aged 85 and over experience severe incontinence ¹
- Labour force participation by people with severe incontinence is less than half that of people without severe incontinence ²
- Over two thirds of people experiencing incontinence do not seek help from a health professional ³, and
- Incontinence is a stigmatised condition with long-term physical and emotional impacts. ⁴⁻⁵

Prevalence, costs and expenditure on incontinence

- The overall total cost of incontinence was \$66.7 billion in 2010, or approximately \$14,014 per person with incontinence. Total costs include direct, indirect, and burden of disease costs ¹
- The estimated direct expenditure on incontinence was \$1.6 billion in 2009 ²
- 83% of direct expenditure was for residential aged care ²
- 30% of the total government residential aged care subsidy is used for people who need assistance with incontinence and toileting ²
- By 2030 over 6.2 million Australians will be affected by incontinence ¹
- By 2031 direct expenditure is projected to increase by 201% ⁶, and
- The number of people in residential aged care with incontinence is expected to almost double from 129,000 to over 250,000 during this same period. ¹

This data is now over a decade old and underestimates the direct, indirect and burden of disease costs of incontinence to the Australian health system and economy in 2021.

Improved continence care reduces health and aged care costs

There is strong international evidence⁷⁻⁸ on the risks and rising costs of untreated or poorly managed incontinence and describing how integrated continence care consumer pathways deliver cost savings by reducing⁹:

- Residential aged care admissions precipitated by incontinence
- Acute hospitalisations for complications of incontinence
- Unnecessary catheterisations and associated urinary tract infections (UTI)
- Incontinence associated dermatitis and pressure injuries linked to poor continence care
- The use of incontinence products through low-cost interventions such as bladder retraining, pelvic floor muscle training and the appropriate use of medications for incontinence.

Incontinence is a major contributor to the recommendations made for admission to residential aged care¹⁰ and its prevalence quickly increases with time in residence.¹¹⁻¹³ These factors drive up aged care costs significantly. In 2008–09, \$1.3 billion (30% of the total government subsidy) was used for people who needed assistance with incontinence and toileting in residential aged care.²

The Australian policy context

Australia is internationally recognised as having a strong history of leadership and investment in promotion of continence health and management of incontinence, with a National Continence Management Strategy established in 1998. In 2021, the Australian Government supports prevention and management of incontinence through three initiatives:

- National Continence Program (NCP)
- Continence Aids Payment Scheme (CAPS)
- Stoma Appliance Scheme.

The NCP was initiated in an Action Plan from 2011 to 2014 and supports several activities, including World Continence Week, the annual National Conference on Incontinence, the National Continence Helpline, and the National Public Toilet Map. CAPS funding assists children aged 5 and above and adults with permanent and severe incontinence to meet some of the costs of their incontinence products. The Stoma Appliance Scheme provides free stoma-related products to people with stomas.

These programs 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 Royal Commission and changing demographics.

Australian state and territory Governments also operate a range of funding schemes for continence products and equipment, with diverse eligibility requirements, supply limits and target groups. A significant unrealised objective of the 2011-14 Action Plan, under the Supporting and Linking action area was to achieve a coordinated approach by state, territory, local and Commonwealth Governments to bladder and bowel health and incontinence management initiatives.

The relationship of the NCP, CAPS and the Stoma Appliance Scheme 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. 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.

Continence health gaps are widening

The Foundation commissioned an environmental scan in 2018 on the status of continence health in Australia and found significant shifts in policy, epidemiology, economics, society, and technology. These have an impact on future continence health needs and the demand for, and supply of, continence health services and support and include:

- a lack of priority placed on continence health in disability, health and aged care policy
- significant gaps in access to specialist continence services
- widespread views of 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
- data gaps limiting the profile of continence health, and
- significant, unrealised scope for prevention throughout the life course

These issues have been exacerbated due to significant national policy developments at the interface of health care, aged care, and disability support. In the absence of up-to-date data and without action to address these issues at a policy level, the costs of incontinence may be much higher than the forward costs projected in 2010.

People at risk of or living with incontinence must not fall through the gaps as the prevalence and costs associated with incontinence increase. National leadership is urgently needed due to the impact on state and territory health services of major national aged care and disability reforms.

Funding under the current National Continence Program expires on 30 June 2021 and its relationship to the NDIS, health and aged care reforms must be clarified as a matter of urgency. A comprehensive approach to continence management must include:

- **prevention and early intervention**
- **support for economic participation by people living with incontinence**
- **standards for safe, quality continence care**
- **workforce capacity building, and**
- **improved data collection.**

In the past Australia has been a leader in continence health promotion and management. However, with the increasing prevalence and associated costs of incontinence, it is essential Government investments and services are adequate to reduce cost and demand impacts on health, aged care and disability services and improve outcomes for individuals and families.

Post-COVID economic priorities

Australia's economy and labour market has been hit hard by COVID-19, and as we enter the post-pandemic recovery phase, the National Skills Commission has identified an uneven recovery across age groups, industries and regions. Based on the Commission's modelling, pre-existing trends, such

as increased adoption of digital technologies and processes and a shift to higher skilled jobs are likely to continue.¹⁴

The Health Care and Social Assistance industry is identified as having many occupations resilient to COVID-19 employment shock. This sector is expected to continue to provide a significant share of new jobs at all levels of skill and qualification with future employment growth in Health Care and Social Assistance expected to increase by 205,900 jobs or 11.6% over 5 years to 2025. This includes a high level of growth, with an increase of 45,300 jobs or 13.1% for nursing professionals, with an increase of 45,300 jobs or 13.1%, and 37,100 jobs or 11.3% for personal care workers over 5 years to 2025.

This strong growth in jobs must be underpinned by robust education and training systems together with the promotion of upskilling and career pathways within the sector. This specifically includes people working in frontline health and aged care jobs and in higher skilled jobs within the specialist continence sector workforce. Australia must also provide support for all its' citizens requiring additional support to re-engage with and re-enter the workforce. The Foundation therefore also makes recommendations for practical actions which support Australia's economic recovery through improved workforce participation for people living with incontinence.

Australia needs a healthcare and social assistance workforce competent in continence care and management

Enabling people to access the right continence health care for them requires a competent workforce able to deliver the care needed, using evidence-based approaches with a person-centred focus.

For older people, the consequences of unsafe and ineffective continence care and incontinence management are:

- increased risk of urinary tract infections (UTI)¹⁵⁻¹⁶
- increased risk of incontinence-associated dermatitis¹⁷⁻¹⁸
- increased risk of pressure injuries^{17,19}
- increased risk of pressure injuries not healing²⁰
- increased risk of falls²¹⁻²⁴
- acceleration of functional decline²⁵, and
- increased risk of depression.²⁶

Adequate education and training to deliver safe and effective continence care and management is essential. Despite the high prevalence of incontinence in people using aged care and disability support services, the workforce, including personal care workers²⁷, enrolled nurses²⁸⁻²⁹ and registered nurses and midwives³⁰ is largely untrained in safe and effective continence care and incontinence management. The Royal Commission into Aged Care Quality and Safety heard evidence of very little training for doctors regarding continence care.³¹

The efficiency and effectiveness of Australia's health care and social assistance workforce will be improved by placing greater emphasis on the demonstrated needs of people living with incontinence and the skills required to meet those needs.

Continence education must be incentivised for all health professionals and personal care workers who work with older Australians and people with a disability.

The Continence Foundation of Australia has brought together internal expertise and expert networks to develop core continence education competencies for nurses and personal care workers. Additional funding is required to develop further training resources and work closely with registered training organisations and regulatory agencies such as SkillsIQ for a national roll out of accredited training for the frontline workforce.

Improved frontline workforce capacity will directly improve the quality of life of people living with incontinence, reduce preventable health complications and unnecessary hospitalisations and delay entry to residential aged care.

The specialist continence health workforce is at risk and Specialist Continence Services are under-resourced

The continence specialist health professional workforce includes medical specialists (urologists, urogynaecologists, colorectal surgeons, paediatricians and geriatricians with specific interest in continence), Nurse Continence Specialists and Continence or Women's, Men's and Pelvic Health physiotherapists.

Services are offered in public and private continence services and practices. There is currently no available data on numbers of specialists across the relevant disciplines, however concerns have been raised with the Foundation about 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 identified above.

The quality of graduate workforce education is directly linked to the quality of care consumers can expect when accessing specialist continence services. The Continence Nurses Society Australia has practice standards³² for Nurse Continence Specialists, but there are no Australian practice standards for multi-disciplinary continence care in primary, secondary and tertiary care in Australia including for GPs who claim MBS subsidies for continence needs assessments.

A 2019 survey³³ of Nurse Continence Specialists (NCS) from around Australia found nearly 40% had concerns regarding job security, downgrading of NCS positions and changes to NCS roles or job descriptions. Respondent concerns included:

- Workplace reviews or restructures with associated actual or feared job losses or cuts to positions, especially in relation to the NDIS
- Downgrading of positions from NCS roles to generalist registered nurse roles but still requiring continence skills, and
- Use of nursing staff without continence qualifications or other disciplines in what were previously NCS roles.

Until recently, Australian registered nurses seeking to specialise as Nurse Continence Specialists had the option of undertaking one of two postgraduate courses:

- Graduate Diploma in Nursing (Continence Nurse Advisor) at Flinders University, and
- Graduate Certificate in Urology and Continence at La Trobe University

These graduate courses are no longer available and there is little scope for registered nurses to gain the necessary specialised knowledge required to become competent Nurse Continence Specialists. Only a single unit of study in Continence Management through the Australian College of Nursing and

a two-unit short course on Urology and Continence through La Trobe University is currently available.³⁴

International evidence from systematic review, qualitative data and expert consensus has been synthesised to develop a service specification framework for continence care.³⁵ Key components include:

- robust referral pathways to improve access to care
- use of comprehensive assessment tools
- initial assessment by nurses specialising in continence care
- access to case coordination
- promotion of self-management and technology; and
- service performance targets based on outcome and operational measures.

Establishing accredited graduate training programs for nurses to become continence specialists is a necessary component of multidisciplinary services to support a holistic and collaborative approach and standards for quality continence care.³⁶ Existing training programs for physiotherapists must also be reviewed as part of continuous quality improvement in support of the multidisciplinary approach.

The Continence Foundation of Australia has the internal expertise and expert networks to bring stakeholders together to develop specialist continence education competencies and standards. Additional funding is required to develop resources to work closely with professional bodies, educational institutes and regulatory agencies such as AHPRA to roll out specialist training nationally.

People living with incontinence have very low levels of workforce participation

For people of working age living with incontinence, productivity losses are estimated at approximately \$34.1 billion due to lower employment rates.¹ Labour force participation is substantially lower for people aged 15–64 who always or sometimes needed assistance with managing bladder or bowel control (20.4%) compared with people who have difficulty but did not need assistance with managing bladder or bowel control (42.3%) and people who had no difficulty at all (56.8%).²

Productivity losses extend to carers assisting people with severe incontinence. The labour force participation rate of primary carers of working age who manage incontinence is lower than for primary carers who do not assist with incontinence (44.3% versus 55.4%).²

As Australia enters a post-pandemic economic recovery phase, we cannot afford people being locked out of the workforce due to a chronic health condition and must make robust attempts to address the barriers preventing their full participation.

Time for national leadership and a new approach in 2021

The Foundation welcomes the Australian Government's commissioning of the Intergenerational Health and Mental Health Study of more than 60,000 Australians as part of the Long Term National Health Plan. However, for this study to provide a truly complete picture of our nation's physical and mental health, it must collect data on the prevalence, physical and mental health and financial impacts of incontinence.

The prevention and management challenges associated with an ageing population and the prevalence of treatable incontinence require a comprehensive policy approach to promoting the health and wellbeing of people with continence health needs across the life course, wherever they live. Services must be available and responsive to the needs of all population groups. An integrated approach can significantly improve quality of life and deliver substantial cost savings to individuals and governments.

It is time for action on a renewed focus on continence health and wellbeing, establishing incontinence as a distinct health care policy priority and directing sufficient resources to prevention and management which reflects its prevalence and impact.

The Continence Foundation of Australia has identified the following urgent actions for the Australian Government:

Immediate Action: A National Strategy on Incontinence: \$7 million over 5 years

A National Strategy on Incontinence funded in the 2021-22 budget, will provide a roadmap to address identified objectives and priorities.

The Strategy would include:

- 1. National Awareness Campaign: \$1 million over 5 years**
- 2. National Workforce Capacity Building Plan: \$0.5 million over 5 years**
- 3. National Economic Participation Plan: \$0.5 million over 5 years**
- 4. National Research Agenda: \$5 million over 5 years**

Immediate Action: A National Strategy on Incontinence: \$7 million over 5 years

The Foundation will work with the Australian Government to urgently establish a National Strategy on Incontinence over 5 years incorporating:

1. A National Awareness Campaign: \$1 million over 5 years

Getting Australians talking about incontinence

The Australian Government must take action under a National Strategy on Incontinence to improve health outcomes for all Australians by getting everyone talking about incontinence, bringing it out of the shadows and making it a topic for discourse through:

- A national stigma reduction campaign to eliminate discrimination against people with incontinence
- Recognition of incontinence as a priority area for improved prevention and management under the National Strategic Framework for Chronic Conditions and National Preventive Health Strategy
- Promotion of the right of all Australians to health care to prevent and manage incontinence, independent of eligibility for the NDIS or aged care services
- A national continence health consultation strategy with consumers, carers and health practitioners to co-design a new national program
- Ongoing and increased funding to deliver the National Continence Program (NCP)

- Expansion and promotion of the National Continence Helpline to offer a more comprehensive and holistic service to consumers and consultation to health professionals, and
- Expanded access to continence health care via telehealth by providing resources for the expanded NCP to leverage opportunities for technologies in self-management and access to care, especially for people in rural and remote areas.

Development of a National Strategy on Incontinence over 5 years funded in the 2021-22 budget, will provide a roadmap to address identified objectives and priorities. Workforce capacity building measures will also support Australia's post-COVID economic recovery.

2. A Workforce Capacity Building Plan: \$0.5 million over 5 years

Increasing the skills of the health, aged care and disability support workforce

The Australian Government must take action under a National Strategy on Incontinence to improve health outcomes for all Australians and boost the skills of the frontline workforce through:

- Improved workforce planning across a range of occupational categories delivering health care, aged care and disability support services.
- Workforce planning to consider the match between the skills, competence, availability and location of the health care and social assistance workforce with the needs of consumers as raised in the Aged Care Workforce Strategy Taskforce report, the NDIS National Workforce Plan and Capability Framework and the report of the independent review of nursing education: Educating the Nurse of the Future
- Collaboration with stakeholders to 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)
- Mandating 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
- Improved focus on evidence-based continence care in all healthcare and social assistance quality and practice standards, including the National Safety and Quality Health Service (NSQHS) Standards, the Aged Care Quality Standards and the NDIS Practice Standards, and
- Promoting person-centred models of care within different settings including community based aged care and disability support services, specialist disability accommodation and residential aged care facilities, in recognition of diverse needs and levels of complexity of care.

Supporting retention and development of a highly skilled specialist continence workforce

The Australian Government must take action under a National Strategy on Incontinence to improve health outcomes for all Australians and arrest decline in the specialist continence workforce through:

- Collaboration with stakeholders to develop a new curriculum standard for recognised post graduate nursing qualifications for continence specialists at graduate certificate, diploma and master's levels
- Consultation with stakeholders to map available specialist continence services to local areas across Australia, with a view to expanding access to specialist continence care for under-served populations and to develop specific service models for rural and remote Australia

- Guaranteed funding under the National Health Reform Agreement for multidisciplinary adult and paediatric continence services across Australia staffed with qualified specialist nursing and allied health staff providing evidence-based continence assessment and care
- Development of minimum standards for provision of specialist continence services in all state and territory public health services
- Addressing the interface of case-mix or block-funded specialist continence health services with individualised funding models in the NDIS and aged care systems
- Expanded models of continence specialist service in-reach to older Australians and people with a disability in residential and community settings to support frontline staff with more complex care, reduce complications of incontinence and prevent unnecessary hospitalisations, and
- Review of MBS Chronic Disease Management data on continence assessments and treatments by GPs and physiotherapists to assess equity of access at a population level.

3. An Economic Participation Plan: \$0.5 million over 5 years

Improving the economic participation of people living with incontinence

The Australian Government must take action under a National Strategy on Incontinence to address the unacceptably low levels of workforce participation by people living with incontinence through:

- Collection and analysis of national data on the individual and systemic factors contributing to low levels of workforce participation by people living with incontinence and their carers
- Continued promotion of the non-discriminatory benefits of workplace flexibility measures, including working from home for both employers and employees
- Increasing access to the Continence Aids Payment Scheme (CAPS) for people in the workforce or seeking employment by removing the eligibility requirement to hold a pension card, aligned to the Stoma Appliance Scheme
- Improving workplace toilet, changing room, showering and continence aid disposal access including work schedule breaks to optimise toilet access and use
- Providing advice and support for employees with incontinence to request reasonable workplace adjustment, and
- Educating employers about reasonable adjustment for employees with incontinence.

4. A National Research Agenda: \$5 million over 5 years

- Inclusion of incontinence as a priority for the Intergenerational Health and Mental Health Study under the Long Term National Health Plan
- 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
- Research of the prevalence and costs of incontinence for the Australian population
- Regular updates of prevalence data to provide accurate measures of demand for continence health services, and
- Improving the focus on prevention through a national audit of access to specialist continence services in Australia to identify service user characteristics and areas of unmet need for specific population groups and geographic areas including:

- Children and young people
- Aboriginal and Torres Strait Islander people
- Culturally and linguistically diverse people
- Lesbian, gay, bisexual, transgender, and intersex people, and
- People living in rural and remote areas of Australia.

Conclusion

Incontinence affects **one in four** Australians and the economic costs are high for consumers and for health and aged care systems. The National Continence Program must be underpinned by robust workforce training and service delivery standards to deliver improved health care and quality of life for people at risk of or living with incontinence. Investment in improved treatment and management will also deliver benefits to future health and aged care budgets.

From evidence given to Disability and Aged Care Royal Commissions, it is clear prevention and management of incontinence is one of the most pressing issues in these sectors. A new national approach to prevention and management of incontinence is an urgent need. The Foundation recommends additional funding for a National Strategy as the most appropriate and effective response to the needs in these sectors. The National Strategy will: promote prevention and management of incontinence for the whole population; provide funding certainty; support a highly skilled and competent workforce and ensure people in specific population groups do not fall through the gaps between systems, and get people talking about incontinence without fear of discrimination or stigma.

The Continence Foundation of Australia brings together Australia's experts in incontinence in a national organisation with capacity to work in partnership with the Australian Government and health authorities in the development of the National Strategy. The Foundation looks forward to working with the Australian Government to deliver improved health outcomes for all Australians.

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