The National Continence Program

ACTION PLAN 2011–2014
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Introduction

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. An estimated 4 million Australians have some degree of incontinence, with the prevalence of incontinence increasing with age in both males and females 1.

The Australian Government continues to support the prevention and management of incontinence through two complementary initiatives, the National Continence Program (the Program) and the Continence Aids Payment Scheme (CAPS). The Program commenced on 1 January 2011.

The Program builds on the National Continence Management Strategy (the Strategy), which was established in 1998 by the Australian Government to provide funding for research and service development initiatives, aimed at prevention and treatment of this important health issue. The direction for the Program is a culmination of Australian Government policy direction, stakeholder input and the findings of an independent evaluation conducted on each individual Strategy project and the Strategy overall. The Program is underpinned by the five principles of prevention, evidence, equity, person-centred care and quality.

The preventative health focus undertaken during the Strategy continues under the Program in light of evidence which suggests that the sustained approach to awareness raising, promotion of bladder and bowel health and workforce support has had a positive impact on people with incontinence, their carers and health professionals 2.

The purpose of this Action Plan is to articulate the principles and objectives of the Program, whilst providing a high-level map for Program activities. The Action Plan outlines a strategic framework to organise the objectives and actions for the Program.

The Action Plan is designed to link with Program communication activities, including consumer and health professional information and resources for the promotion of bladder and bowel health, and the prevention, assessment and effective management of incontinence. The Action Plan seeks to increase public awareness of the Program, provide information and improve transparency. The Action Plan is available to all stakeholders and the general public.

Incontinence

Urinary incontinence is defined by the International Continence Society (ICS) as the "complaint of any involuntary leakage of urine". Urinary incontinence is further defined by the ICS according to specific symptoms, such as stress urinary incontinence, urge urinary incontinence, mixed urinary incontinence, nocturnal enuresis, post-micturition dribble, or continuous urinary incontinence. Other types of urinary incontinence may be situational.

Faecal incontinence is defined as "any involuntary loss of faecal material". Faecal incontinence is currently not further defined by the ICS.

The International Children’s Continence Society (ICCS) defines urinary incontinence in children as daytime or nocturnal incontinence / enuresis. It can be continuous, that is, constant urine leakage, or intermittent, which is urine leakage in discrete amounts. Enuresis, often called bedwetting, may be sub-grouped into monosymptomatic and non-monosymptomatic enuresis. The ICCS further defines specific conditions for children with urinary incontinence, including overactive bladder and urge incontinence, voiding postponement, underactive bladder, dysfunctional voiding, obstruction, stress incontinence, vaginal reflux, giggle incontinence and extraordinary daytime urinary frequency.

Incontinence is a common health problem in Australia. In 2003, an estimated 3.8 million Australians living in the community experienced some type of urinary incontinence. Of the 3.8 million people living in the community with urinary incontinence it is estimated that:

- 64,464 people experienced very severe urinary incontinence;
- 176,380 people experienced severe urinary incontinence;
- 723,120 people experienced moderate urinary incontinence; and
- 2,877,562 people experienced slight urinary incontinence.

In 2003, an estimated 202,130 people living in the community experienced frequent or very frequent faecal incontinence and approximately 128,826 people living in residential aged care experienced difficulty or problems with bladder / bowel control.

Females are more likely than males to experience incontinence, and women account for two thirds of people who are likely to experience severe incontinence. Approximately 545,000, or 2.8% of adults in Australia, either living in supported accommodation or in the community, experience severe urinary or faecal incontinence. Incontinence is also more common in older age groups and is one of the major factors for admission to residential care.

6 Ibid, p 320.
8 Ibid, p 58.
9 Ibid, p xix.
10 Ibid, p xvii.
**Risk Factors**

There are many conditions that are associated with an increased risk of incontinence.

**Urinary Incontinence**

The primary risk factors for urinary incontinence include:

- pregnancy (both pre and post-natal women), childbirth and parity;
- menopause;
- obesity and body mass index;
- lower urinary tract symptoms including urinary tract infections;
- constipation;
- specific types of surgery such as prostatectomy (removal of all or part of the prostate) and hysterectomy (removal of all or part of the uterus and/or ovaries);
- reduced mobility preventing access to or using the toilet;
- cognitive impairment;
- neurological and musculoskeletal conditions such as stroke, Parkinson’s disease, spinal cord injury, multiple sclerosis and arthritis;
- other health conditions such as diabetes, heart conditions, respiratory conditions, and prostate problems; and
- some medications.

**Faecal Incontinence**

A risk factor for faecal incontinence is urinary incontinence. Other risk factors are similar to those of urinary incontinence, but also include chronic diarrhoea and dementia.

**Under-reporting of Incontinence**

Under-reporting of incontinence is thought to be common and many people feel unable to discuss incontinence with their health practitioner. Pearson et al (2002) reported that the major reasons for under-reporting of continent problems are embarrassment and social stigma, a lack of knowledge about incontinence and a reluctance of many health practitioners to raise the issue. Awareness of incontinence in the Australian community, including promotion of incontinence awareness by primary health care professionals, is important to reduce barriers to disclosure.

**Expenditure for Incontinence**

In 2003, the estimated cost of incontinence in Australia in the health and residential aged care system was $1.5 billion. The majority of this cost is for residential aged care and continence.

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14 Ibid, p iii.

15 Ibid, p iii.

The National Continence Program 4

Development of the National Continence Program

The Australian Government supports better health and active ageing for all Australians. The Program will be implemented in the ever changing context of public health, health promotion and prevention, health reform, workforce and social policy directions. As bladder and bowel health cannot be considered in isolation from a person's general health status, the Program will link with initiatives which encourage and support Australians to take better care of their health. Activities which prevent and reduce lifestyle risk factors and chronic disease also lead to improved bladder and bowel health, a fundamental for continence.

Continence Aids Payment Scheme (CAPS)

The Australian Government provides targeted initiatives to assist older Australians to maintain independent, active and healthy lives. The CAPS and the Program are complementary initiatives which aim to promote preventative health messages for bladder and bowel health and assistance to enable older people to lead independent, active and healthy lives and to remain in their homes and in the community. The CAPS and the Program also provide support and assistance to specific groups of various ages within the broader population.

The CAPS assists eligible people who have permanent and severe incontinence to meet some of the cost of their incontinence products. The CAPS provides increased choice and flexibility to people with incontinence to purchase products from a supplier of their choice. This is consistent with the Government’s Charter of Rights and Responsibilities for Community Care. The activities of the Program support the objectives and implementation of the CAPS through communication about incontinence, available assistance, management strategies and health professional advice and education. The Program further provides support for clients, carers and health professionals to make informed choices in relation to incontinence management and treatment.

Policy Context

The Program falls within the Department of Health and Ageing’s Portfolio Outcome 4, Aged Care and Population Ageing, Program 4.4, Community Care. Targeted initiatives under Program 4.4 help older people lead independent, active and healthy lives; seek to promote preventative health messages and services; provide information and services that aim to educate the community; support the workforce; help older people to more fully engage in their communities; and help to address and challenge perceptions about decreasing capacity associated with ageing by maintaining a focus on preventative health.

The National Continence Program promotes the importance of bladder and bowel health across the lifespan and recognises that incontinence affects people of all ages. The Program adopts a whole of life approach, considering both children and adults at risk of developing, or living with, incontinence.

Framework

Aim
The overall aim of the Program is to improve awareness, prevention and management of incontinence so that more Australians and their carers can live and participate in the community with confidence and dignity.

Principles
The Program is underpinned by five principles:

<table>
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<tr>
<th>Principle</th>
<th>Description</th>
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<tbody>
<tr>
<td>Prevention</td>
<td>The foundations of bladder and bowel health are laid in childhood, linked to general health and are an essential component in preventing incontinence.</td>
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<tr>
<td>Evidence</td>
<td>Current evidence forms the basis of Program initiatives; new activities are informed by evidence; and findings are disseminated.</td>
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<tr>
<td>Equity</td>
<td>Regardless of age, background or geographic location, support for people with incontinence should be accessible.</td>
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<tr>
<td>Person-centred care</td>
<td>A person-centred care approach acknowledges that personal dignity and choice is imperative in supporting people with incontinence.</td>
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<tr>
<td>Quality</td>
<td>High quality, timely and relevant continence services are provided across the continuum of care, by appropriately trained health professionals and other care workers, and appropriately supported and informed carers.</td>
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Objectives
The overarching objectives of the Program are to:

- promote bladder and bowel health and prevention messages across the lifespan;
- increase awareness of bladder and bowel health and access to appropriate information, support and resources within the population;
- focus on ensuring that the needs of all target groups are embedded into the Program;
- improve access to quality incontinence care; and
- develop a national, collaborative approach to the promotion of bladder and bowel health and incontinence management.

Action areas
The key recommendations from the Independent Evaluation of the Strategy have directly influenced the development of action areas for the Program. The key achievements and recommendations arising from the evaluation of the Strategy and the link to the action areas of the Program are shown in Figure 1.

The activities of the Program will be organised under three specific action areas:

- Communicating and Promoting;
- Implementing; and
- Supporting and Linking.

Each action area is supported by specific objectives and actions to be undertaken during the life of the Program.
Key Priority Action Areas

Communicating and Promoting

The specific objectives under the Communicating and Promoting action area are to:

- enhance community awareness of bladder and bowel health and incontinence management through multiple communication channels; and
- increase levels of awareness about bladder and bowel health and prevention and management of incontinence across the lifespan.

Actions

- Develop an evidence-based communication strategy that raises awareness of bladder and bowel health and incontinence management and the availability of information and support.
- Conduct communication activities to raise public awareness of risk factors, bladder and bowel health and the importance of healthy lifestyle behaviours.
- Provide access to information and support to all target groups through multiple communication channels.
Implementing

The specific objectives under the *Implementing* action area are to:

- increase the knowledge of bladder and bowel health and incontinence management for health professionals, care workers and carers; and
- facilitate the availability of current research, standardised terminology, clinical tools and evidence-based innovations for incontinence care.

**Actions**

- Improve access to workforce training, education and support.
- Provide opportunities for primary care health professionals, rural and remote health workers, Aboriginal and Torres Strait Islander health workers and carers to access training, education and support.
- Promote the use of consistent and standardised terminology.
- Disseminate current research, evidence-based innovations and clinical tools.
- Investigate, develop and pilot models of community based care.
Supporting and Linking

The specific objectives under the Supporting and Linking action area are to:

- achieve a coordinated approach to the work of state, territory, local and Commonwealth Governments in relation to bladder and bowel health and incontinence management initiatives;
- assist people living with incontinence by supporting activities that facilitate community participation; and
- strengthen the capacity of, and partnerships and collaboration with, key stakeholders.

Actions

- Strengthen the capacity and expand the role of the Continence Foundation of Australia as the national peak body.
- Develop linkages and identify opportunities for joint activities with other relevant organisations.
- Establish and strengthen relationships with relevant governments, community and industry groups.
- Communicate Program priorities and progress to support stakeholder activities at a national, state and territory and local level.
- Provide information and support to Continence Aids Payment Scheme clients.
National Continence Program Strategic Model

The National Continence Program falls within the Department of Health and Ageing’s Portfolio Outcome 4, Aged Care and Population Ageing, Program 4.4, Community Care. Targeted initiatives under Program 4.4 help older people lead independent, active and healthy lives.

AIM

Improve awareness, prevention and management of incontinence so that more Australians and their carers can live and participate in the community with confidence and dignity.

PRINCIPLES

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<tbody>
<tr>
<td>Prevention</td>
<td>Evidence</td>
<td>Equity</td>
<td>Person-Centred Care</td>
<td>Quality</td>
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PROGRAM OBJECTIVES

Promote national bladder and bowel health and prevention messages across the lifespan.

(Equity and Prevention)

Increase awareness of bladder and bowel health and access to appropriate support, information and resources within the population.

(Equity and Person-Centered Care)

Focus on ensuring that the needs of all target groups are embedded in the Program.

(Equity and Person-Centered Care and Quality)

Improve access to quality incontinence care.

(Pevention; Evidence; Equity and Quality)

Develop a national, collaborative approach to the promotion of bladder and bowel health and incontinence management.

(Pevention; Evidence; Equity; Person-Centered Care and Quality)
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<tr>
<th>ACTION AREA OBJECTIVES</th>
<th>OUTCOMES</th>
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<tbody>
<tr>
<td><strong>(A)</strong> Enhance community awareness of bladder and bowel health and incontinence management through multiple communications channels. <em>(Communicating and Promoting)</em></td>
<td>Appropriate, timely evidence-based information is provided to all target groups.</td>
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<tr>
<td><strong>(B)</strong> Increase levels of awareness about bladder and bowel health and prevention and management of incontinence across the lifespan. <em>(Communicating and Promoting)</em></td>
<td>Increased knowledge for health professionals, care workers and carers.</td>
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<tr>
<td><strong>(C)</strong> Increase knowledge of bladder and bowel health and incontinence management for health professionals, care workers and carers. <em>(Implementing)</em></td>
<td>Increased availability of current research, standard terminology, clinical tools and evidence-based innovations for incontinence care.</td>
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<tr>
<td><strong>(D)</strong> Facilitate the availability of current research, standardised terminology, clinical tools and evidence-based innovations for incontinence care. <em>(Implementing)</em></td>
<td>A coordinated approach is achieved.</td>
</tr>
<tr>
<td><strong>(E)</strong> Achieve a coordinated approach to the work of state, territory, local and Commonwealth governments in relation to bladder and bowel health and incontinence management initiatives. <em>(Supporting and Linking)</em></td>
<td>People with incontinence are supported to participate in the community.</td>
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<tr>
<td><strong>(F)</strong> Assist people living with incontinence by supporting activities that facilitate community participation. <em>(Supporting and Linking)</em></td>
<td>Capacity of stakeholders is strengthened.</td>
</tr>
<tr>
<td><strong>(G)</strong> Strengthen the capacity of, and partnerships and collaboration with, key stakeholders. <em>(Supporting and Linking)</em></td>
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Stakeholder Engagement and Collaboration

Strategic advice and guidance from key stakeholders will support the achievement of Program outcomes. Mechanisms will be developed to ensure that the implementation of the Program is informed by the views of key stakeholders including consumers, state and territory and local governments, key Commonwealth stakeholders, the Continence Foundation of Australia, other professional bodies, non-government organisations, industry and academia.
Key Partners and Stakeholders

Continence Foundation of Australia
The Continence Foundation of Australia (CFA) is the national peak body for bladder and bowel health promotion, incontinence management and advocacy. The CFA manages the National Continence Helpline (NCHL) which is a critical component of the Program. The NCHL, which comprises a team of continence advisors who are available by phone, offers free, confidential advice about bladder and bowel health and incontinence management, in addition to local referrals, leaflets and product information.

This service is for people of all ages, their carers, parents and families, health professionals, healthcare organisations and all Australians.

States and Territories and Local Government
State and territory governments also support bladder and bowel health and incontinence management in Australia. This support is primarily through direct service provision in the community and hospital sector. Local governments perform an important role in service delivery and communicating bladder and bowel health and incontinence management messages across individual regions by promoting incontinence management in their local communities.

Health Professionals and Organisations
Health professionals assist in improving long-term health outcomes for people at risk of developing or living with, incontinence. Health professionals and organisations encourage bladder and bowel health, prevention, screening for people at risk of developing incontinence and provide education about the management of incontinence. General practitioners, pharmacists, nurses and nurse practitioners, midwives, physiotherapists, occupational therapists and other allied health professionals, aged and community workers and Aboriginal and Torres Straight Islander health workers all play a pivotal role in incontinence management and prevention.

Australia, through its representation and participation in the International Continence Society, is a significant contributor to the international body of evidence and information on bladder and bowel health and incontinence management.

The Program will continue to build on linkages developed with all governments and other portfolio areas in the education and aged care sector, industry (including manufacturers), product suppliers and other national, state and territory based public health and workforce initiatives. The Program will work to ensure that bladder and bowel health and effective incontinence management is embedded within mainstream healthcare delivery and residential aged care.
Background and History

The National Continence Management Strategy (the Strategy)

The Strategy was established in 1998 by the Australian Government to provide funding for research and service development initiatives, aimed at prevention and treatment of incontinence. The Strategy was delivered as a three phased approach.

Since its establishment, the Strategy has supported over 130 national research and service development projects, including clinical research and quality related projects in addition to activities aimed at improving community awareness and studying the extent of incontinence in the community. The evidence base established from these research projects is reflected in the direction of the Program. Phases 1, 2 and 3 of the Strategy have been independently evaluated, and the recommendations, combined with stakeholder input and findings from market research, have informed the design of each subsequent phase.

During the Strategy, there was an increase in the number of consumers seeking help for their incontinence and increased uptake of information via communication channels such as the National Continence Helpline, Bladder & Bowel website and the National Public Toilet Map 18. These core activities are pivotal to the success of the Program as they are the central communication channels for access to information, resources and support. The Program will continue to build on the positive linkages with stakeholders and multidisciplinary collaboration across many projects developed during Phase 3 19.

Evaluation

An Independent Evaluation was completed in Phase 3 of the Strategy, which obtained evidence through a multi-factorial approach, using systematic project review, analysis of project based data and evidence gathering processes 20. The evaluation also incorporated a review of progress towards achieving key performance indicators and recommendations from the previous phases. The Strategy was found to be effective in achieving the desired effects of raising awareness, supporting the workforce and improving both consumer and health professional practice 21.

The key achievements and recommendations arising from the Independent Evaluation of the Strategy and the integration of these elements into the action areas of the Program are depicted in Figure 1.

19 Ibid, p 3.
21 Ibid, p 3.
Achievements

The Strategy implemented a number of awareness raising initiatives for the Australian community, and was successful in increasing the number of consumers seeking help for their incontinence. 80% of respondents were highly satisfied with the way the National Continence Helpline met their needs and the Bladder & Bowel website has been shown to play an important role in providing access to all target groups, including resources in other languages.

Recommendations for future progress

Ensure adequate accessibility to community awareness and education initiatives through multiple modes of access. Continue to review the effectiveness of such access for all target groups.

Implement a broad communications strategy to raise awareness of current practices in continence management and the availability of information and support services.

Conduct communication activities to raise public awareness of risk factors and continence management options and the importance of healthy lifestyle behaviours to support bladder and bowel health.

Achievements

The professional knowledge of health workers was increased by 16-54% as a result of training initiatives, with improvements in levels of confidence and engagement in the practice arena.

Recommendations for future progress

Enhance the scope, reach and efficiency of workforce education, targeting health professional groups that have received limited continence specific education during Phase 3 of the Strategy. This particularly includes undergraduate curricula, GPs, practice nurses, physiotherapists, community care professionals, occupational therapists and other allied health professionals, and Aboriginal and Torres Strait Islander health workers.

Address the lack of standards, guidelines and consistency in use of terminology.

Increase the use of data/tools produced through the Strategy.

Explore options to increase the capacity of primary healthcare professionals through improvements to training and education curricula.

Improve access to training, education and support for medical and healthcare personnel, especially those who live in rural/remote areas and for those from a culturally and linguistically diverse background.

Pilot and evaluate some models for community-based care that were identified in Phases 1 and 2.
Achievements

Linkages and collaboration were developed, building the collaborative capacity of stakeholders, increasing multidisciplinary collaboration and links with external organisations. Stakeholder involvement was seen across all projects.

Recommendations for future progress

In partnership with relevant stakeholders, identify opportunities for dissemination of accurate, consistent messages on bladder and bowel health and continence management.

Establish and strengthen partnerships with relevant government, community and industry groups.

Develop links to communication activities around lifestyle risk factors at national, state and territory and local government levels to ensure that continence management options are incorporated into future planning and development initiatives.
Quality Improvement & Evaluation

All evaluation activities will be undertaken in line with this Action Plan. Evaluation of individual activities and the action areas of the Program will be incorporated in an overall evaluation. The Program will aim to ensure consistently high quality across all activities under the action areas.

Further Information

For further information on the National Continence Program:

- Contact the National Continence Helpline – 1800 330 066
- Visit: http://www.bladderbowel.gov.au

Other useful resources and information:

- National Public Toilet Map: http://www.toiletmap.gov.au

Feedback from stakeholders is welcomed and encouraged.