



**Continenence  
Foundation  
of Australia**

# National Dementia Action Plan

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Rowan Cockerell, CEO

SUITE 1, 407 CANTERBURY ROAD, SURREY HILLS, VIC 3127

## Introduction

The Continence Foundation of Australia (the Foundation) welcomes the opportunity to respond to the consultation on the development of the *National Dementia Action Plan* (Action Plan) being undertaken by the Australian Department of Health and Aged Care.

The Foundation supports this development and understands it to be an important step to ensuring that the voices of people with dementia, as well as their families and carers are reflected in Australia's priorities for action.

Additionally, we see it as an opportunity to highlight the prevalence of incontinence in people living with dementia, to gain recognition of the significant impact this has on them, and the people who care for them, and to improve the quality of life of people with dementia who also experience incontinence.

The Continence Foundation of Australia (the Foundation) is the peak body for promoting continence (bladder and bowel control) health. The expertise of the Foundation in education, awareness, information and experience of putting people at the centre of program design, means that we are best placed to represent the interests of individuals, carers, and health professionals in relation to incontinence and the significant impact incontinence has for people living with dementia.

## The Foundation's Submission

The Foundation supports the proposed principles and agree that these should be reflected in the Action Plan.

However, the Foundation holds concerns, that while the actions proposed are intended to improve the lives of people with dementia, they do not address the high prevalence of incontinence amongst people living with dementia, and the significant impact it has on them, as well as those who care for them.

By omission, we consider it to be a serious gap in the Action Plan, that there is no acknowledgement of the high prevalence and impact of conditions that are co-morbidities associated with dementia, such as incontinence. We suggest that this omission be addressed to facilitate holistic care and support for people living with dementia, and for those who provide care.

The Action Plan is an important step to enabling people with dementia to live free of stigma and discrimination and to participate fully in their communities, but this cannot be fully realised without also addressing the impact of incontinence on people with dementia, as well as their carers and families.

We believe that dementia care, treatment and support would be enhanced by recognition of incontinence under all the Objectives for the Action Plan, however we particularly focus on the following areas where addressing incontinence needs of people with dementia would have most impact and benefit:

**Objective 1: Tackling stigma and discrimination**

**Objective 3: Improving dementia diagnosis and post diagnostic care and support**

**Objective 4: Improving treatment, coordination and support along the dementia journey**

**Objective 5: Supporting people caring for those living with dementia**

**Objective 6: Building dementia capability in the workforce**

**Objective 7: Improving dementia data**

## Recommendations:

The Continence Foundation of Australia recommends the following be considered in the finalisation and implementation of the National Dementia Action Plan:

- **That the lack of recognition of the impact of health conditions associated with dementia, including incontinence, be addressed to facilitate holistic care and support for people with dementia.**
- **That, in conjunction with dementia-friendly design principles, specific continence supports including incontinence product disposal bins, change rooms, shower facilities and adult change facilities, be incorporated into design of public spaces to support full participation of people with dementia.**
- **That dementia specific support and referral pathways being established through Primary Health Networks include recognition of other health and community support needs and facilitate access to other specialist assessment services, including continence services for post-diagnostic care and support.**
- **That, in addition to the proposed actions and existing resources available to carers, information be developed to assist them to support the continence needs of the person they care for. This should include awareness of the National Continence Helpline and its provision of advice, information and support from Nurse Continence Specialists on continence related issues.**
- **Dementia data collection should be enhanced by collecting data on health conditions (such as incontinence) which are often experienced throughout the dementia journey. This data will inform policy and program development, supporting holistic and comprehensive care pathways for people living with dementia.**

## Incontinence and Dementia

Incontinence is inappropriately, and incorrectly, considered to be only an aspect, or consequence of, dementia. It is in fact a significant health condition for people living without dementia as well as those living with dementia, is more prevalent in older age than is dementia, and is as directly influenced and impacted by design as is dementia.

- Incontinence is one of the top three critical factors identified for older Australians needing to transition from home-based aged care to residential aged care.<sup>1</sup>
- Two studies on people with dementia and incontinence identified the following challenges<sup>2,3</sup> that can be addressed with design interventions:
  - inability of the individual to act in a timely way in response to the sensation of the need to void,
  - inability to locate, recognise and use toilets, manage personal activities of toileting, and
  - inappropriate management of soiled clothing and resistance to help with toileting. The initial response of carers, in one study, was shown to be to resort to containment of incontinence for ‘occasional accidents’. However, the worsening of symptoms over time obligated carers to take on a more proactive but also more taxing role compounded by additional financial and emotional impacts<sup>2</sup>.

- Residents with dementia have high needs for physical assistance with toileting and continence care. Australian research found that 76% of residents diagnosed with dementia had the highest rating of need for assistance with continence, and 68% with toileting. In comparison, of residents without dementia, 51% had the highest care need rating with continence and 47% with toileting<sup>4</sup>.
- Sixty-nine per cent of residents with dementia were recorded as having more than three episodes of urinary incontinence daily or scheduled toileting, while 46% of residents living with dementia had more than four episodes of faecal incontinence weekly or scheduled toileting<sup>5</sup>. It may be more difficult to provide continence care for people with dementia because the condition may affect their awareness of their bladder and bowel needs.

## The Foundation's response to the Objectives

### Objective 1: Tackling stigma and discrimination

The Foundation supports the Action Plan's proposal to create an Australian society which is inclusive of people with dementia, and which enables them to fully participate and to live independently, with dignity and respect.

We suggest, however, that consideration should also be given the significant impact which amplifies the distress and embarrassment attached to experiencing incontinence, and the additional burden, psychologically, physically and socially, this may have on people with dementia. People with incontinence frequently experience isolation, and barriers to participation in public spaces and recreational activities; this is compounded by the difficulties and barriers experienced by people living with dementia who also experience incontinence.

We welcome the promotion of dementia-friendly design principles for private and public spaces which includes strategies to ensure that bathrooms and toilets meet the needs of people with dementia, who may also be experiencing incontinence. However, there should also be incorporation of other specific continence supports including incontinence product disposal bins, change rooms that also act as shower facilities, and adult change facilities to better support people experiencing incontinence.

### Recommendation

- **We recommend that, in conjunction with dementia-friendly design principles, specific continence supports including incontinence product disposal bins, change rooms that also act as shower facilities, and adult change facilities, be incorporated into design of public spaces to support full participation of people with dementia.**

### Objective 3: Improving dementia diagnosis and post diagnostic care and support:

The Foundation supports the focus and initiatives designed to assist people post diagnosis to prepare and develop strategies for changes they are experiencing, and to enable them to manage their condition and continue to participate in the community. We particularly welcome the recognition that accessing toilets may be a problem for people even in the early stages of dementia, through the *Forward with Dementia* website.

However, without recognition of the impact of health conditions associated with dementia, and actions to support appropriate assessment of these conditions, the quality of life of people with dementia will be reduced. We suggest that support and treatment for people with a diagnosis of dementia can be enhanced by the use of care plans that include screening tools, and early routine health assessments.

Incontinence is a common condition in the Australian population, and highly prevalent amongst people with dementia, but it can be treated and proactively managed. Early assessment and diagnosis of incontinence could alleviate many problems experienced by people with dementia and their carers and families. However, many GPs are not confident or adequately trained to identify or address conditions such as incontinence. An Australian study found 43% of GPs received a moderate or higher level of training or education in urinary incontinence but only a low 9% for faecal incontinence.<sup>6</sup> Additionally, 56% self-reported insufficient skills to address faecal incontinence highlighting large gaps in proficiency for both types of incontinence<sup>6</sup>.

It is essential that care pathways for dementia diagnosis also include recognition of other health conditions that people living with dementia experience. Dementia specific support and referral pathways through Primary Health Networks already facilitate access to other specialist assessment services, such as for specialist services such as Cognitive Dementia and Memory Services (CDAMS) throughout Victoria, and similar access and referral to continence services should be encouraged.

### **Recommendation**

- **We recommend that dementia specific support and referral pathways being established through Primary Health Networks also facilitate access and referral to specialist assessment services, including continence service for post-diagnostic care and support.**

### **Objective 4: Improving treatment, coordination and support along the dementia journey.**

We endorse the Action Plan's focus on improving treatment, coordination and support along the dementia journey. However, as we suggest above, without recognition of the impact of co-morbidities in conjunction with dementia, such as incontinence, the effectiveness of treatment, coordination and support will be impeded.

We recognise that navigating the health, disability and aged care system can be a complicated and overwhelming experience for people living with, or caring for someone with, dementia and is compounded by hospital and aged care environments which are not always supportive or inclusive to those living with dementia, as is the case for people experiencing incontinence.

People with dementia who also experience incontinence should have access to continence services that can address their continence needs with person-centred support. Incontinence is a health condition capable of early recognition, is potentially preventable and is always manageable.

Incontinence impacts people across the life-course, increasing in prevalence with age. It is one of the top three critical factors identified for older Australians needing to transition from home-based aged care to residential aged care.<sup>1</sup> Aged Care residents with dementia have high needs for physical assistance with toileting and continence care. Australian research found that 76% of residents diagnosed with dementia had the highest rating of need for

assistance with continence, and 68% with toileting. In comparison, of residents without dementia, 51% had the highest care need rating with continence and 47% with toileting<sup>4</sup>.

Alongside the quality of support and care, the design of health and care environments can improve or impede person-centred care for people living with dementia and incontinence. Appropriate design enables best practice, person-centred care and support in all aspects of healthcare and is a major influence on the capacity of healthcare providers and staff to provide high quality care and support to older people living with conditions such as dementia and incontinence.

## **Recommendations**

- **We recommend that the impact of incontinence along the dementia journey be recognised under the Action Plan, and incorporated into actions to improve treatment, coordination and support for people with dementia, who also experience incontinence.**

## **Objective 5: Supporting people caring for those living with dementia**

The Foundation agrees that carers should have access to support and training to undertake their caring role and maintain their own health and wellbeing. Supporting carers in their role to provide care and support for people living with dementia should acknowledge the complex care needs that people with dementia have, including management of incontinence.

The Australian Institute of Health and Welfare found that three in four carers spent 40 hours or more per week caring for someone with incontinence.<sup>7</sup> Primary carers who assisted with managing incontinence reported feeling weary and lacking energy or being worried or depressed at significantly higher rates than carers who did not usually assist with managing incontinence.<sup>8</sup>

Support, resources and educational opportunities should be provided to carers not only on dementia but also on incontinence. The Foundation has a range of resources to support carers including the National Continence Helpline.

### **Recommendation:**

- **That information be developed to assist them to support the continence needs of the person they care for. This should include awareness of the National Continence Helpline and its provision of advice, information and support from Nurse Continence Specialists on continence related issues, and other supports such as Continence Aids Payment Scheme (CAPS), and various State schemes.**

## **Objective 6: Building dementia capability in the workforce.**

The Foundation agrees that building workforce capability is essential to delivering high quality, evidence-based, person-centred care for people with dementia, including those who experience incontinence.

Education and training in both dementia and continence care should be a mandatory requirement for all staff and professionals who provide care and support for people with a disability and older Australians accessing primary and aged care services. There is a serious shortage of skills and knowledge within the aged care workforce, particularly around the impact and management of incontinence. This will undoubtedly impact on the quality of care for people with dementia.

In Australia in 2016, 70% of direct residential aged care workers were personal care workers, who provide the most care yet are unlikely to be adequately trained in safe and effective continence care.<sup>9</sup> The consequences of ineffective and unsafe continence care can increase the risk of urinary tract infections, incontinence associated dermatitis and pressure injuries within a Residential Aged Care Facility (RACF) setting, and the risk of falls and functional decline in both an RACF and community setting.

An Australian study found that 69% of residents with dementia had more than three episodes of urinary incontinence daily or scheduled toileting and 45.7% of residents with dementia had more than four episodes per week of faecal incontinence or scheduled toileting.<sup>7</sup> Assisting aged care recipients with toileting places a high workload on care workers but the benefits of reducing the incidence of incontinence and the associated risks such as incontinence associated dermatitis as well as the increased care needs for skin care and changing continence aids, is often overlooked when building workforce capability.

The Foundation endorses the importance of focusing on dementia in training across all disciplines. We find the development of the Action Plan to be an important step to enabling people with dementia to live free of stigma and discrimination and to participate fully in their communities, however this cannot be realised without also addressing the impact of incontinence on people with dementia, as well as their families and carers. To achieve the suite of objectives identified in the Action Plan we believe building capability of the workforce should also include training to address continence care and incontinence management, to provide best quality care for people with dementia, and all care recipients.

Addressing barriers which affect personal care workers and direct care staff to assist people with the need to go to the toilet in a timely manner is key to both the prevention and management of incontinence in people with dementia. This can be accomplished through both appropriate training of staff to be able to undertake continence assessments, develop continence care/management plans including toileting programs to assist with toileting, and in the design of aged care facilities and hospitals to promote continence.

#### **Recommendation:**

- **Building the capability of the workforce should also include training to address continence care and incontinence management, to provide best quality care for people with dementia, and all care recipients.**

#### **• Objective 7: Improving dementia data**

The Foundation agrees that data pertaining to dementia is inadequate for informing policy and programs and must be improved to support innovations in dementia diagnosis, treatment and care. Strengthening data on dementia diagnosis and management with an emphasis on improving quality of life for people who are currently living with dementia, and for those who develop dementia in the future, will enable health professionals and carers to provide care that is person-centred and cognisant of, and adaptable to, a person's individual requirements.

The Foundation suggests that data which supports the detection, prevention, assessment, care, and support for people with dementia could be enhanced by also collecting data on health conditions diagnosed in people living with dementia. This information provides opportunity for data informed decisions to be made to improve policy and programs and supports so that people living with dementia, their carers and families will be able to access appropriate services and support, in a timely way and which enhances their quality of life living with dementia.



## Recommendation:

- **Dementia data collection should be enhanced by collecting data on health conditions (such as incontinence) which are often experienced throughout the dementia journey. This data will inform policy and program development, supporting holistic and comprehensive care pathways for people living with dementia.**

## Conclusion

The Continence Foundation of Australia welcomes the development of the National Dementia Action Plan and commends the work undertaken to address the issues impacting on people living with dementia, and their carers and families.

We support the proposed vision, principles and actions identified in the Action Plan, and the focus on the person-centred approach outlined to support people with dementia, their families and carers. However, we believe that efforts to enable people with dementia to live free of stigma and discrimination and to participate fully in their communities would be enhanced by also addressing the impact of incontinence on people with dementia, as well as their families and carers.

We consider it to be a serious gap in the Action Plan, that there is no acknowledgement of the high prevalence and impact of incontinence for people with dementia throughout the dementia journey. This should be addressed to ensure the Action Plan can achieve its stated intentions of improving the quality of life of people living with dementia.

We look forward to working with the Australian Government, and Dementia Australia to support the implementation of the Action Plan and to addressing the issues for people with dementia who live with incontinence.

## References

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