

## ***Caregiving, Dementia and Incontinence***

*Joan Ostaszkiwicz, RN, GCert Cont Prom, GCertHE, MNurs-Res, PhD  
National Ageing Research Institute*

### Key highlights:

- Up to one third of people with dementia experience incontinence at some point in the disease trajectory.
- Social taboos about incontinence can leave those with dementia and caregivers struggling to find helpful information and support.
- A new free online resource is available that addresses emotions and beliefs about incontinence, and provides information about maintaining continence and managing incontinence for those with dementia.

People with dementia who experience incontinence deserve care that treats them with dignity and respect. Almost one third of people with a diagnosis of dementia experience difficulties with bladder or bowel function (1). These difficulties can have significant impacts on quality of life for both the individual and caregivers (2-5).

Despite the prevalence and impact of incontinence for people with dementia and caregivers, there is limited information available for support including strategies to delay or prevent incontinence, or information addressing the emotional and physical aspects managing incontinence (6).

To address gaps in current evidence and support, a research team from the [National Ageing Research Institute](#) (NARI) in collaboration with [Deakin FutureLearn](#) in Australia designed and disseminated a Massive Open Online Course (MOOC) on '[Caregiving, Dementia and Incontinence](#)'. The course, which is available to people from anywhere in the world, tackles the physical, psychological and psychosocial aspects of caregiving associated with dementia and incontinence.

Developed with the input of those living with dementia, caregivers and healthcare professionals, the course delivers free online training for both family and community caregivers which has received incredibly positive feedback.

With no prior experience or qualifications required, participants can gain knowledge, skills and resources to assist with toileting, promote continence, and manage incontinence. The MOOC is a multimedia experience, with visual and audio learning tools, and includes a platform for social interaction with other caregivers.

The course provides helpful information about:

- Coping with the lived experience;
- Basics of bowel and bladder function;
- Promoting healthy bowel and bladder function and assisting with toileting and hygiene;
- Using continence aids and incontinence products, and protecting the skin;
- Coping at home, out and about, and accessing information and support

In the 8 months since its release in August 2022, the MOOC has attracted more than 1,900 users across 69 countries – far exceeding initial expectations.

The MOOC provides people from around the globe with access to vital information and tools to support loved ones living with dementia and incontinence.



**For further reading:**

1. Grant RL, Drennan VM, Rait G, Petersen I, Iliffe S. First diagnosis and management of incontinence in older people with and without dementia in primary care: a cohort study using The Health Improvement Network primary care database. *PLoS Med.* 2013 Aug;10(8):e1001505. doi: 10.1371/journal.pmed.1001505.
2. Drennan, V.M., Cole, L. & Iliffe, S. A taboo within a stigma? a qualitative study of managing incontinence with people with dementia living at home. *BMC Geriatr* 11, 75 (2011).  
<https://doi.org/10.1186/1471-2318-11-75>
3. Cole L, Drennan VM. Living with incontinence: The experience of people with dementia. *Dementia.* 2019;18(5):1826-1839. doi:10.1177/1471301217731171
4. Juliebø-Jones P, Coulthard E, Mallam E, Archer H, Drake MJ. Understanding the Impact of Urinary Incontinence in Persons with Dementia: Development of an Interdisciplinary Service Model. *Adv Urol.* 2021 Jun 19;2021:9988056. doi: 10.1155/2021/9988056.
5. Murphy C, De Laine C, Macaulay M, Hislop Lennie K, Fader M. Problems faced by people living at home with dementia and incontinence: causes, consequences and potential solutions. *Age Ageing.* 2021 May 5;50(3):944-954. doi: 10.1093/ageing/afaa262.
6. Drennan, V.M., Greenwood, N., Cole, L. et al. Conservative interventions for incontinence in people with dementia or cognitive impairment, living at home: a systematic review. *BMC Geriatr* 12, 77 (2012). <https://doi.org/10.1186/1471-2318-12-77>



I am a Registered Nurse and an academic. I lead a program of research at the National Ageing Research Institute that encompasses research on dementia care, continence care, loneliness and social isolation, carer support, and the development and evaluation of knowledge resources to promote best practice. My aim is to build a global alliance to systematically tackle the neglected,

stigmatized and complex biopsychosocial phenomenon of continence caregiving. The focus is on ethical, safe, person-centred continence care that upholds the rights and dignity of older people who require services and supports to maintain continence or manage incontinence. For further information or if you would like to contribute to my vision, please contact me at: [j.ostaskiewicz@nari.edu.au](mailto:j.ostaskiewicz@nari.edu.au)

]