

Continence care matters for people living with dementia

In this article, Alzheimer Europe reflects on some of the key issues around continence care for people with dementia and identifies some of the ongoing efforts to improve the quality of their care and treatment. Dianne Gove, Director for Projects, then provides some reflections on the work of Alzheimer Europe on this topic in recent years.

Incontinence is a widespread condition affecting some 50 million people across the EU, with more than 15 million informal carers taking care of some of these people living with the condition. A significant number of people living with dementia in the EU are likely to experience issues with incontinence at some stage, with no total cure currently available, despite medical and pharmaceutical research into this area.

Approach to continence care

Despite the scale of the number of people affected by the condition, it is an area which is often not discussed or adequately considered in the context of dementia. There are four key aspects which must be considered in relation to addressing incontinence:

- Prevention
- Detection
- Assessment of incontinence
- Management of continence problems with toileting and containment

Continence care must always be in accordance with the needs of people with dementia and carers. It is essential that the primary consideration in any approach must be to do what is best for the person with dementia, taking into account their individuality, their wishes and the promotion of their individual autonomy, wellbeing and independence.

This requires awareness, training and education of informal caregivers and professionals so they may appropriately assess the toileting and containment needs of the person with dementia, as well as identifying and

suggesting suitable management or preventative measures. Health and social care professionals must also take into consideration the needs and wishes of informal carers who often play a vital role in ensuring good continence care for people with dementia living at home. Due to the progressive nature of dementia, regular re-assessment is essential to ensure the suitability and effectiveness of the measures put in place.

As part of this process, people with dementia (and where appropriate their informal carers) must be involved in all aspects of their assessment and the delivery of continence care. Where proxy decision-making powers are in place, procedures should be followed in line with policy and legislation in that country to involve the proxy.

Looking to the future of toileting and containment care

Research and development processes in this field have advanced, aiming at improving the care pathway for toileting and containment care, especially for people who require care services, with the ambition to keep people self-managing for as long as possible. The optimisation of the care pathway is helped by the use of technology enabling a good assessment and an improved delivery of person-centred care.

New technologies have the potential to assist people with advanced dementia who experience difficulties in expressing their need to go to the toilet or have their pad change managed. One such example of a recently developed assessment tool is a digital health

technology product that monitors the voiding pattern and the volume of urine lost, providing the base for developing a person-centred toileting and containment care plan. Another approach which utilises digital health technology is a change indicator, which can inform an informal carer or professional that the pad is saturated and need to be changed.

Digital health technologies, in combination with other incontinence products, can help ensure the good quality care for persons with dementia which meets their needs. This way good outcomes can be achieved for the person with incontinence and for informal carers, whilst ensuring effective use of available budgets provided by health care payers. If a care pathway with the support of digital health technologies are to be implemented as part of care for people with dementia, a significant shift both in policy and practise is required.

Towards the implementation of good practice

In the policy context, Alzheimer Europe joined a roundtable event in 2019, facilitated by Essity Hygiene and Health AB, along with AGE Platform Europe, Eurocarers and the European Institute for Women's Health. The group identified key issues affecting the populations they represent, the required solutions and the policy and decision makers who were best placed to affect change.

This discussion culminated in a call for action, calling on decision makers at local, regional, national and EU levels to take action to put in place the necessary person-centred care provisions that can help manage incontinence, to support the best possible quality of life and make the best possible use of existing budgets and care resources.

Recommendations within the call to action were broad in nature, including:

- Urging health authorities to promote the World Health Organization (WHO) Integrated care for older people (ICOPE) framework.
- Demanding that health care payers ensure that out-of-pocket expenses for individuals are minimised and ensure that individuals and informal carers have

choice and control over the selection of containment products and overall care with respect to toileting needs.

- Encouraging education bodies to ensure that the training of health care

professionals responsible for assessment and delivery of care are sufficiently skilled and knowledgeable about prevention and daily management strategies for incontinence.

The Call to Action can be accessed at: www.bit.ly/ContinenceCallToAction

Dianne Gove, Director for Projects, explores the importance of good continence care and highlights Alzheimer Europe’s work in this area



Just over five years ago, Alzheimer Europe set out to explore the issue of continence care for people with dementia living at home. At the time, little work had been done on continence care for this group of people. Recommendations and guidelines for the continence care of other groups (such as older people, people with cognitive impairments or frail older people) in other settings (e.g. hospital or residential care settings) cannot simply be applied to people with dementia living at home.

Together with a team of clinical and academic experts in continence care, policy making, general practice and dementia, including a person with dementia, and with the support of Essity (formerly SCA Hygiene Products AB), we developed guidelines on continence care for people with dementia living at home.

The report and recommendations emphasised the need to promote independence, as far as possible, and to avoid assumptions about dementia, the abilities of people with dementia and their wishes. Continence care must always be based on an individual assessment. Incontinence should not be seen as an inevitable aspect of dementia. It should always be investigated and a diagnosis of dementia should not, on its own, rule out any specific approach.

The experts recognised the importance of appropriate and affordable, good quality

continence products, but also that these must not be the only solution offered to people with dementia. Rather appropriate continence products may be one part of a comprehensive continence care plan. This includes looking at how the environment contributes towards incontinence, at techniques to help prevent actual incontinence, and at treatment and even surgery.

Following on from this work, Alzheimer Europe has contributed towards the development of key performance indicators (KPIs) to measure outcomes for the daily management of toileting and containment within a range of care settings. It is hoped that these KPIs will contribute towards improving the quality of continence care for people with dementia. Another, important area of work has been the development of policy recommendations, as mentioned above, and Alzheimer Europe is currently a member of an advisory board for a study to



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compare the efficacy of different types of continence products.

Good continence care is key to respecting the human rights and dignity of those affected by continence problems but incontinence remains a stigma in many parts of Europe. Alzheimer Europe is keen to promote open discussion about this topic and encourages health and social care professionals, as well as policy makers, to take a proactive approach to addressing this sensitive topic so as to provide appropriate and timely support for people with dementia and carers.

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