

PRESS RELEASE

EMPOWERING PEOPLE WITH INCONTINENCE AND THEIR CARERS TO LIVE INDEPENDENT AND DIGNIFIED LIVES AT HOME AND IN THE COMMUNITY

Study conducted in six European regions contributes to better understanding of how to improve the care for people with incontinence in their daily lives at home and in the community.

Patient involvement, knowledge and provisions based on patient profiles were found to be key in enabling people with incontinence and their carers to live independent and dignified lives.

Berlin, 19 April 2016 – The results of a major pan-European study which gives insight into the quality of continence care services and provisions was launched today at the 6th *Global Forum on Incontinence: “Sustainable health and social care: The role of Continence Care in enabling Independent and Dignified living”*.

The study was conducted by AGE Platform Europe, a European network representing over 40 million older people in Europe, and SCA. Entitled *Management for Containment - A review of current continence care provisions*, the study was conducted amongst people with incontinence and informal carers in six regions in Germany, Poland, England and Spain. It aimed to provide an understanding of the existing knowledge patients and carers had about the containment products that are available, and to what extent they were involved in the decision about which product type to use.

The main findings of the study were:

- 1 in 4 said the product type offered did not always sufficiently support them when taking part in the activities of daily life
- 43% felt that their product type did not always sufficiently support them when taking part in work activities
- 41% experienced disturbed sleep due to product type
- Nearly 40% felt they had no choice on what product type they could use
- 3 out of 4 needed to pay for additional products themselves

“In today’s context of demographic ageing, it is increasingly important to take action to ensure that the support for managing incontinence fully meets the individual’s needs and preferences”, Anne-Sophie Parent, Secretary General of AGE Platform Europe, said. “There is a lot of room for improving the care of people with incontinence by involving them much more in the decision-making when selecting containment products”.

The study highlighted three key factors that could lead to greater user independence and satisfaction in daily management:

- information and knowledge about the different product types
- involvement in selecting the type of product
- tailored funding provisions based on patient profiles and needs

Partners:



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The findings of the study aligned closely with the conclusions drawn from an Expert Roundtable held in 2015. Eight leading European patient and civil society organizations¹ joined forces and identified six recommendations to improve the care of people with incontinence in a Joint Position Statement² calling to:

- Recognize continence care as a human right which enables people to live independent and dignified lives
- Increase awareness and understanding of incontinence among users and informal carers
- Improve information about incontinence and continence care provisions
- Enable choice, involvement and empowerment of people affected by incontinence
- Develop continence-friendly urban/community and home environments
- Support and prioritize a research agenda on incontinence

Eurocarers, the European network representing informal carers participated at the roundtable. John Dunne, President of the organization stated: “Incontinence is a prime example of a challenge to restore independence and dignity and keep people active in, and contributing to society”.

ENDS

Media Enquiries

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¹ AGE Platform Europe, Eurocarers, European Institute of Women’s Health (EIWH), European Multiple Sclerosis Platform (EMSP), Health First Europe (HFE), Alzheimer Europe, European Brain Council (EBC), International Federation for Spina Bifida and Hydrocephalus (IF SBH), European Federation of Crohn’s & Ulcerative Colitis Associations (EFCCA), International Alliance of Patients’ Organizations (IAPO)

² http://www.age-platform.eu/images/stories/Publications/papers/JointPositionStatement_on_Incontinence_2015.pdf

Partners:



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About the Global Forum on Incontinence

The Global Forum on Incontinence (GFI) is a high-level stakeholder forum that brings together policy makers, patient and civil society organizations, health and social care professionals, experts, and payers from all over the world to discuss and improve the organization and management of continence care at home and in the community. The 6th edition of the GFI will address the burden of incontinence compared to other chronic diseases, the cost of inaction, the ‘state of the nation’ of continence care provision today, and the importance of a more person-centered, functional needs- and outcome-based approach to continence care that will enable people with incontinence, and their carers, to live independent and dignified lives at home and in the community.

The GFI is organized by Svenska Cellulosa Aktiebolaget (SCA) in partnership with AGE Platform Europe and Eurocarers, and with the endorsement of the following organizations: International Continence Society, International Alliance of Patients’ Organisations, European Association for Directors and Providers of Long-Term Care Services for the Elderly, European Centre for Social Welfare Policy and Research, European Institute of Women’s Health, Canadian Nurse Continence Advisors Association, European Union Geriatric Medicine Society, European Health Management Association, Health First Europe, Zentrum für Qualität in der Pflege, Bundesarbeitsgemeinschaft Selbsthilfe, Care England, International Federation for Spina Bifida and Hydrocephalus.

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