



## Putting in place provisions for person-centred daily continence care: A Call to Action

Incontinence is a widespread chronic condition affecting some 50 million people across the EU. More than 15 million informal carers take care of these individuals. At present, the vast majority of those living with incontinence do not find a cure, despite medical and pharmaceutical efforts and developments (1). Moreover, provisions for daily continence care is suboptimal across the board.

**Therefore, putting in place accessible, person-centred provisions for the day-to-day management of incontinence is key to support both persons living with the condition as well as their carers.**

*While the importance of prevention - taking a life-long approach - and cure of incontinence is recognised, underlined and advocated by the organisations above, this Call to Action deliberately focuses on daily continence care as the area where those that are currently living with the condition need the most support. The biggest gains in quality of life for the individuals concerned and efficiency in the use of scarce health, social and long-term care resources can currently be achieved in this context. In addition, appropriate continence care, making use of the right products, adapted to individual needs can make substantial contributions to sustainable environments.*

Recent studies (2) have clearly shown that there is a mismatch between individual toileting and containment needs on the one hand side and access to solutions on the other, even where these exist. However, improvements in service delivery for daily toileting and containment management can lead to significant increases in the quality of life of individuals and their carers and will also result in substantial savings for health care systems as self-management and care efficiency are increased. In other words, appropriate continence care relates to 'value for money' – both in terms of care staff required, volume of products used (with a positive impact on environment through waste reduction) and facilitating active lives of those living with incontinence, enabling them to contribute to their communities as well as to society as a whole.

A person-centred health and social care approach based on individual needs assessment, delivered by well-trained health care professionals, also making use of supportive technology, can yield positive outcomes, in terms of improving the quality of life of those living with the condition and that of their carers as well as for optimal use of existing health and social care resources.

**The above organisations call on those responsible for the provision of care across the EU – at local, regional, national and EU level - to take action to put in place the necessary person-centred care provisions that can help manage incontinence and prevent the potential consequences of suboptimal care, supporting quality of life and making the best possible use of existing budgets and care resources.**

**Did you know that:**

- ✓ Incontinence affects both women and men (Total 8,7% people 20+, ♀ 12,4%, ♂ 5%) (3)
- ✓ The condition does not only affect older people but is highly prevalent in older people aged 60 years and over. Recent population-based studies report 9.9%-36.1%. (4)
- ✓ 40% of persons with incontinence dependent on care of others live in their own homes (split: 50% independently at home, 40% care dependent at home, 10% care dependent in an institution) (5).
- ✓ 1 in 5 carers looking after a person with incontinence report a significantly lower quality of life than other carers(6).
- ✓ Dignity and privacy are fundamental human rights which apply to every human being including persons living with incontinence.
- ✓ Personalised toileting and containment management improve quality of life and reduce loneliness, depression, dropping out of work...
- ✓ Not being able to stay in employment because of incontinence or the need to provide support to a person living with the condition exacerbates inequalities in terms of pay and social security, also later in life.

**Recommendations for improving quality of life and ensuring the best use of resources****At national/regional/local level:****Health authorities should:**

- ✓ Develop policies that allow for thorough assessment practices for people in need of daily support with toileting and containment strategies, allowing for the development of person-centred strategies, to facilitate the best day-to-day management of the condition; promote WHO ICOPE recommendations on urinary incontinence (7).
- ✓ Carry out audits, in order to determine whether and how incontinence features in health and long-term care systems, as well as to explore if care guidelines are in place and are being implemented, taking into account gender and age factors;
- ✓ Enable individuals with incontinence and their informal carers to participate fully in society by taking into account the notion of 'reasonable accommodation': with some adjustments to private homes and public spaces and an adequate provision of incontinence products, persons with incontinence and their informal carers can be empowered to live a normal and productive life.

**Payers should:**

- ✓ Put in place provisions allowing for person-centred health and social care in relation to daily continence management as optimal provisions will help those affected to continue to live active and dignified lives. At the same time, they ideally should not be depending on family carers' help in this intimate and personal space and if unavoidable the burden for family carers need to be minimized.
- ✓ Address out of pocket expenses for individuals: as appropriate incontinence products are needed daily, expenses can become costly; moreover, having appropriate products from the start will support self-management and care efficiency and help prevent potentially negative outcomes (e.g. leakages, skin problems, carers' time, isolation and depression).
- ✓ Enable individuals and their informal carers to have choice and control over the selection of containment products and overall care with respect to toileting needs.

### Training/education bodies should:

- ✓ Ensure proper training of those health care professionals responsible for assessment and advice and those that deliver the day-to-day care. Training curricula on incontinence should also include enabling good daily management and prevention of possible negative consequences, such as dependence, urine track infections, incontinence associated dermatitis and others. The aim should be to support individuals living with incontinence to best manage and cope.

### At EU level:

#### **The European Commission should take action in the following areas as follows:**

##### *Research:*

- ✓ Ensure that Horizon Europe will support qualitative as well as quantitative research on chronic conditions - such as incontinence – to assess its social and economic impact on patients and carers, health and social care systems and society as a whole and provide evidence-based policy recommendations, including factors like gender and age.
- ✓ Include continence-friendly urban design (public toilets and signage) in the ‘Smart Cities’ strand of Horizon Europe, also to help EU Member States adapt to their rapidly ageing population.

##### *Internal Market:*

- ✓ Ensure a focus on the assessment and delivery of person-centred toileting and containment strategies in harmonised health and care training curricula, for nurses and other professional carers.

##### *Health:*

- ✓ Include daily continence care in the Health Programme; a recent publication on outcome measures for toileting and containment strategies (8), addressing what good care looks like could be a useful starting point for exchange of good practice between and capacity building in Member States.
- ✓ Promote dissemination of positive outcome measures with respect to toileting and containment strategies, e.g. as part of the Chrodis+ programme;
- ✓ Ensure a focus on continence management in all relevant EU initiatives and programmes, particularly those with a focus on elderly care, including the various Expert and Advisory Groups (e.g. Better Ways of Investing in Health);

##### *Employment and Social Affairs:*

- ✓ Include the topic of incontinence and its management into all initiatives on long-term care (e.g. the ‘Social’ OMC, the work of the SPC and the implementation of the European Pillar of Social Rights (Article 18 on the right to long term care));
- ✓ Pay attention to the impact on incontinence in employment related initiatives e.g. Health and Safety at Work) and mobilise the European Social Fund to support skills development of carers and health care professionals.

#### **The European Parliament:**

- ✓ Ensure inclusion of incontinence and daily continence care into relevant Commission proposals;
- ✓ Support and host meetings on this topic of the various relevant Intergroups and Interest Groups, to increase visibility of the topic and spur payers and policymakers into action.

### At global level:

- ✓ The WHO and OECD should pay more attention to incontinence and continence care in their work and research on long term care, with a specific focus on the benefits of person-centred toileting and containment strategy provisions for individuals, their carers and society at large.

*The roundtable of patient and civil society organisations with an interest in the topic of daily continence care, organised to develop this call to action, has been facilitated by Essity Hygiene and Health AB.*



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