

**The future of health and social care: towards a new care pathway for Europe's ageing societies.
*The example of incontinence.***

28 January 2015 | 08.00 – 9.30 – European Parliament, Member's Salon, ASP Floor 0

- Summary Report -

On 28 January 2015, AGE Platform Europe and Eurocarers organized a breakfast meeting on *“The future of health and social care: Towards a new care pathway for Europe's ageing societies. The example of incontinence”* The event was hosted by **MEP Jean Lambert (UK, Group of the Greens/European Free Alliance)**, and co-chaired by MEP Marian Harkin (Ireland, Group of the Alliance of Liberals and Democrats for Europe) and MEP Heinz K. Becker (Austria, Group of the European People's Party). The event was initiated and supported by SCA Hygiene products.

The meeting brought together policy leaders in health and social care to learn more about the burden of incontinence on patients, carers and society and to discuss a new and innovative care pathway for Europe's ageing societies. Incontinence is a very common and distressing health and social care issue that deserves our full attention as it affects the lives of over 25 million people in Europe today, of which the majority is 65+.

MEP Jean Lambert opened the meeting and pointed out that a key challenge for the future is to develop care pathways that support better integrated health and social care services for an increasing number of older people. In too many countries, we see barriers between the two areas rather than co-ordination. She added that, despite its prevalence, incontinence is still a 'silent disease' and that the aim of the meeting is to find ways to raise awareness and provide solutions for better continence care.



In his introduction, **John Dunne, President of Eurocarers**, highlighted that incontinence still remains largely unaddressed outside the privacy of homes. The first step to improve care is therefore to 'normalise' incontinence. He stressed that, besides the economic and social impact incontinence has on patients, the burden and impact on the quality of life of carers needs to be addressed as well.

Anne-Sophie Parent, Secretary-General of AGE Platform Europe, followed by fully endorsing Mr. Dunne's statements. She also argued for better health and social care integration and for better acknowledgement of the needs of persons with incontinence in urban planning to help create age friendly environments (e.g. bins in men's toilets) to help older people with incontinence remain actively involved in their communities.

Mr. Ralf Jacob, Head of the Active Ageing, Pensions, Healthcare and Social Services unit of DG Employment, Social Affairs & Inclusion at the European Commission presented the work and the perspective of the European Commission on the future of long term care (LTC) in the EU, addressing the need for more efficient and better



integrated health and social care services in LTC. He pointed out the recently published report by the Social Protection Committee on “Adequate Social Protection against Long-Term Care Needs in an Ageing Society”. The report notes that in most countries, long-term social care is regarded and treated differently from health care. It is either not covered at all or only to a limited extent by the same collective protection as health care. Mr. Jacob furthermore highlighted that dependency on LTC has a significant health-related economic and social risk for individuals and for their families who often act as carers. In this context, he particularly gave the example of incontinence, a disease which has a major impact on the quality of life and social integration of both the patients and their carers. He concluded by saying that the European Commission is looking to work together with policy-makers to find solutions to better integrate social and health care and reduce dependency through rehabilitation, prevention and self-management.

Representing the voice of patients, Mr. Archie Noone then delivered a lively and inspiring testimony about the profound impact of incontinence on the daily lives of older people as they seek to live active, healthy and independent lives and age with dignity. He particularly highlighted the lack of knowledge about incontinence and indicated the importance of talking about incontinence in the home, community, professional and policy setting. Mr. Noone also noted the additional financial burden of incontinence, and remarked that financial support from payers is essential to support care management.



Prof. Adrian Wagg followed and provided an excellent example of an integrated care model in ageing services, which shows that more cohesive care systems could make a difference for patients and carers. He introduced the Optimum Continence Service Specification (OCSS), which provides a set of 9 recommendations to improve the care of people with incontinence:

- Develop robust referral pathways to ensure that patients receive timely, equitable and effective care
- Use nurse specialists for initial assessment and treatment; if specialist continence nurses are not available, existing healthcare professionals should be trained
- Use a case co-ordinator to ensure a “patient-centred” approach
- Specialists should play a key role in quality governance, training and dissemination of best practice
- Use a comprehensive standardized assessment of user, product, and usage-related factors to assess needs with regards to containment products
- Promote amongst patients the use of self-management tools
- Make use of technology to enable self-care, connect patients and caregivers, and to enable providers to better monitor progress and troubleshoot problems
- Payers should ensure that care standards are incentivized to ensure the highest quality of continence care
- Establish accredited programmes of training in continence care nursing.

Prof. Wagg also presented the results of a health economic study conducted by Erasmus University in the Netherlands. The study aimed to determine the costs and effects of delivering continence care using the OCSS when compared with the current care pathway. The study showed that implementing the OCSS helps reduce the level of incontinence, improve the quality of life of the patients, and reduce costs both from a payer’s perspective as well as from a societal perspective.

MEP Marian Harkin then opened the floor for a lively debate amongst speakers and participants on the possible barriers and solutions to improving the quality and delivery of care for Europe’s ageing population, highlighting incontinence and the OCSS as an example. Participants generally agreed on the need for care coordination and highlighted the role of health literacy and assistive technology to raise awareness and improve knowledge about incontinence. In this context, a representative of the Health & Wellbeing unit of DG Communications Networks, Content and Technology (CNECT) gave examples of several projects funded through Horizon 2020 which seek to address digital health literacy. The European Innovation Partnership on Active and Healthy Ageing (EIP-AHA) is a good example of a bottom-up approach also working on integrated care.

AGE Platform highlighted the broader socio and economic consequences of living with or caring for people with incontinence, such as employability, or depression. In this context, AGE Platform stressed the need to gather and present data about the economic impact of incontinence to make the case for policy action. Eurocarers and a representative of the European Parliament, on the other hand, pointed to the increasing socio-demographic mass of people living with incontinence and argued for a human rights and social care approach as well. It was also pointed out that people living with incontinence are generally a silent group, making the disease and its consequence unknown and therefore not a policy priority. Finally, Eurodiaconia highlighted that many good local

initiatives and best-care practices which are not scaled up to the national level, often because of budgetary reasons.



MEP Heinz K. Becker concluded the meeting. He highlighted that raising awareness and improving knowledge about incontinence is the first step needed in order to take action at political level. In this sense, he noted that the work of the Social Protection Committee was instrumental to help lift the issue at EU-level and pointed out the three points of focus which are important: innovation, prevention, and the socio – economic benefits. He also congratulated Prof. Wagg for his presentation on the OCSS, which provided an excellent example of an integrated care model. MEP Becker argued that politicians need to recognize the relevancy of incontinence and proposed a one hour working session with the key stakeholders, including policy makers and NGOs to move the issue forward and propose concrete actions. Finally, he encouraged all participants to contribute to raising awareness about incontinence at EU level.