



Position paper on a patient-centred, affordable and sustainable system for incontinence* aids

Summary

Incontinence currently affects millions of Europeans and, as our populations grow older, it will touch the lives of millions more. While Member States are responsible for the funding and delivery of health services, the EU can play an important role in improving patient care in this field by embedding key principles in health systems across Europe.

These include recognising incontinence as a set of diseases, ensuring that all patients affected by incontinence get the care they need, supporting the provision of information to patients about the condition and its treatments, and fostering a patient-centred approach to incontinence care which values transparency and patient choice.

The purpose of the paper is to raise awareness, initiate and facilitate constructive dialogues amongst all stakeholders including patients and their carers, clinicians, payers, policy makers, the industry, and promote efficient collaboration in finding the best potential solutions for incontinence aids.

What is incontinence?

Incontinence is one of humanity's most strongly tabooed topics, it may affect individuals of all ages, and there is a wide range of severity and symptoms. It is not a life-threatening disease, but the different symptoms may seriously influence physical, psychological, and social well-being. The World Health organization (WHO) has classified incontinence as a set of diseases, and has included different types of it in its ICD (International Classification of Diseases) as well as in its ICF (International Classification of Functioning, Disability and Health) classification.

Urinary incontinence

Urinary incontinence is defined as "*any involuntary leakage of urine*" by the International Continence Society (ICS).

Faecal and anal incontinence

Faecal Incontinence (FI) is the involuntary loss of faeces – solid or liquid. Anal Incontinence (AI) includes these events as well as the involuntary loss of flatulence or wind, which is felt by many patients to be an equally disabling disorder¹. Anal incontinence in most cases co-exists with urinary incontinence, and is usually a consequence of surgical intervention, dementia or other degenerative conditions.

Who is affected?

¹ 4th International Consultation on Incontinence, 2008

There are currently no exact estimates on the numbers of people who live with chronic incontinence, but European studies estimate that between 4% and 8% of the total population are affected. The following prevalence figures combine the number of people who suffer from temporary and chronic² incontinence.

Urinary incontinence

The estimated prevalence of urinary incontinence (UI) in middle-aged and older women in the general population appears to be in the range of 30% to 60% and the percentage increases with age. For example, recent studies reported that one quarter of young women, half of middle-aged and post-menopausal women, and three quarters of elderly females in nursing homes, experienced some degree of involuntary urine loss.

The prevalence of daily UI ranges from 5% to 15%. It is estimated that one in seven women aged over 70 who are institutionalised experience daily UI. The burden of incontinence in Europe is expected to grow due to the ageing population and increasing life expectancy.

Age is associated with a steady increase in prevalence among women. The epidemiology of UI in men has not been investigated to the same extent as for females, but it appears that incontinence is at least twice as prevalent in women as in men.³

Anal incontinence

The prevalence of anal incontinence also increases with age, but is present in all age groups and in both genders ranging from 1.5% in children to more than 50% in nursing home residents.⁴

Medical devices available

To help to manage incontinence, there are distinct ranges of medical devices available for individuals affected: absorbent products and appliances

The indication for the use of both absorbent products and appliances depends on

- The type/nature of incontinence;
- The severity of the incontinence;
- The patient's personal circumstances (physical condition, size, mobility care situation etc.);
- The patient's and carer's skills and abilities.

The absorbent products are developed for the purpose of absorbing urine and faeces. Main types are:

- Female products (for urine only)
- Male products (for urine only)

² Chronic: Incontinence which lasts over a sustained period and is not directly linked to a certain event in the patient's life. (e.g.: pregnancy, surgery, infections)

³ 4th International Consultation on Incontinence, 2008)

⁴ 4th International Consultation on Incontinence, 2008)

- Inserts (for urine and faeces)
- All in one products (for urine and faeces)
- Belted briefs (for urine and faeces)
- Pants or “pull on” products (for urine and faeces)

Appliances are categorized into:

- Indwelling bladder drainage devices (suprapubic catheters and transurethral catheters)
- Intermittent transurethral catheters and intermittent self-catheterising systems (ISC)
- Urinary condoms with leg bags / night bags
- External urine drainage devices for men and women
- Anal irrigation devices

E-Health/self-care solutions also exist including:

- E-health system to monitor and record the pelvic floor exercises - tangible sensor device, a web portal and smartphone app
- Sensor technology built into the absorbent products to measure urine voids (frequency & quantity) – the information is transmitted to a web portal, which generates a voiding report of the patient that enables to develop patient centered care plan.

Barriers

According to Article 129 of the European Union Treaty, the organisation and delivery of health services and medical care are the responsibility of the Members States. Disparities between, and within, Member States lead to inequality in how patients are cared for. This can also make it difficult for patients suffering from incontinence to understand their entitlements and to navigate complex bureaucratic reimbursement systems.

Some key barriers must be overcome if patients are to receive optimal care:

- ✓ Missing or not used clinical and care guidelines
- ✓ Chaotic, non-transparent patient pathways
- ✓ National/regional differences in access to information and products/service solutions
- ✓ Limited access to most suitable and/or new generation incontinence products/services

What is our perspective?

By integrating the following principles into systems all over Europe, we would move towards patient-focused, sustainable and affordable systems for quality incontinence care:

1. **Incontinence should be recognised as set of diseases, clinical and care guidelines should be in place and followed.** More awareness of the growing problem of incontinence should be developed and guidelines for the distribution of adequate information of available products/services and

good examples of incontinence care should be disseminated. Educational packages regarding incontinence care should be made available for patients, carers as well as for health and social care professionals who often are in contact with patients and their family carers.

2. **Patients should be provided with products and services that are medically and socially adequate, necessary, and identified based on individual assessment.** Personalised product selection should be granted and (if available) be based on internationally recognised standards (ISO 15621, ISO 16021). There is an urgent need for a comprehensive person-centred needs assessment for carers including entitlement to care that takes into consideration the practical and emotional aspects of caring. At the national level, measures should be developed to ensure accessibility to quality products at an affordable price.
3. **Patients and carers should have access to product and service information and have freedom to choose the products/care they need.** Patients who live with incontinence and use medical devices are a heterogeneous group because the cause of their incontinence and their individual needs differ greatly. As there is no one-size-fits-all solution, patients/carers must have access to all available information and products. In order to secure freedom of choice, all direct communication channels should be opened for sharing information with patients and carers. Patient information will increase the level of knowledge, appropriate product use and patient adherence; thus leading to a more efficient utilisation of public resources.
4. **Continence care should not be considered a commodity business.** Continence care is burdensome and time consuming activity, that significantly increases the difficulties derived from caring for an old disabled person.
 - Decision makers should be more aware of the possibilities to relieve the burden of so many carers of patients dealing with an illness in combination with incontinence. They should look into more solutions on regional and local levels for respite breaks for informal carers as well as other support systems for the family networks.
 - Hospitals and other care institutions should plan training courses and services to accompany the carers of old people discharged from hospital wards in order to assess the type and frequency of leakages, to help carers manage them and choose the right products and to avoid bedsores. Training should be developed in consultation with those using the products and their carers.

About EDANA

EDANA is the international association serving the nonwovens and related industries. With member companies producing everything from raw materials to finished products, and in categories from medical to automotive, filtration, construction, to hygiene and personal care and beyond, **EDANA** provides an environment beneficial to sustainable and profitable growth of individual companies and the industries we serve.

For more information visit www.edana.org

About Eucomed

Eucomed represents the medical technology industry in Europe. Our mission is to make modern, innovative and reliable medical technology available to more people. Eucomed promotes a balanced policy environment that enables the medical technology industry to meet the growing healthcare needs and expectations of society. Eucomed members include both national and pan-European trade and product associations as well as medical technology manufacturers.

For more information visit www.eucomed.org

About Eurocarers

Eurocarers, the European Association Working for Carers, seeks to represent and act on behalf of all informal carers, irrespective of their age or the particular health need of the person they are caring for. It shall pursue philanthropic, educational and scientific ends with regard to the representation of carers.

For more information visit www.eurocarers.org

About WFIP

The World Federation of Incontinent Patients (WFIP) is a global federation of national patient organizations for sufferers of incontinence and related pelvic floor disorders. The Federation is dedicated to promoting worldwide the interests of such patients and patient associations. The Federation provides its individual member associations with the most comprehensive and up-to-date information and guidelines and educational resources. It seeks international cooperation and consensus via advocacy, public health education, and contact with official and scientific bodies and other patient advocacy groups.

For more information visit www.wfip.org