In Europe during the last 50 years, life expectancy has grown by an amazing rate, so much so that some scientists have talked about the "Broken limits to life-expectancy", arguing that it is no longer conceivable to set physiological limits to human aging. The rise in life expectancy is certainly a positive factor, but needless to say, the period of one's illness or disability also increases as well. Therefore, in order to assess the actual benefits of the demographic aging process one refers to life expectancy in terms of years of good health (**HLY - Healthy Life Years**), an indicator that measures "**residual life free from disability and disease**". It is estimated that by 2050, in the EU, the number of people over 65 years of age will increase by 70% and the number of over-80s will increase by 170%. All this has important implications because it will be necessary to meet a growing demand for care, the national health (welfare) services will need to be adapted to the requirements of an aging population whilst ensuring, at the same time, that they remain economically sustainable in today's Europe featuring a reduced workforce due to the international economic crisis. In this social and economic context, incontinence (urinary and faecal) also involves considerable costs to the national health (welfare) services.

As a consequence of this, the national health (welfare) services must address three major challenges:
1. the rising costs of health care;
2. the growing number of healthcare users;
3. the increasing social and health needs of the population.

The European Commission has reacted to these important challenges by setting three major goals for the near future:
1. access to healthcare for everybody;

2. a high level of quality healthcare;
3. national financial sustainability (welfare and healthcare systems).

Incontinence is one of **the last medical taboos that we have not yet managed to eradicate** anywhere in the world; it is a secret that we cannot tell anyone about, not even our own GP, partner or friends. It is estimated that in the 27 EU countries over **36 million people** suffer from urinary incontinence, 60% of whom are women and the number of people affected is on the increase due to the lengthening of one's life span. Nowadays, incontinence is seen as a natural consequence of either advancing age or diseases that often provoke the condition (diabetes, obesity, vaginal and urethral inflammation, senile dementia, Alzheimer's, etc.). But, as often happens, there are doctors who **should offer advice to incontinent patients** but who pay little attention to incontinence-related disorders and, in many cases, have limited knowledge of the problem and show little interest in the "**world of incontinence**". For them incontinence is perceived as being not very gratifying work, of little interest, almost unpleasant and poorly paid. In relation to the care of the elderly, the situation in Europe involves young women, particularly from countries outside the EU, caring for older women. In addition, there are many problems, some of which are listed below, also affecting the status and condition of the personnel providing care for elderly incontinence-sufferers and this is a worrying state of affairs:
a. the aging of the population in Europe and worldwide is fuelling a rapid increase in the number of elderly people, even in developing countries (Africa and Asia);
b. cuts to social spending made each year by different national governments and the consequent reduction in budget allocated to social spending has led to a reduction in the number of older people being assisted;
c. patients are increasingly cared for at home and for longer periods than in the past and this implies admission to nursing homes at a later age which in turn increases the risk of being affected by multiple diseases, whereby these patients require greater specialist care;
d. thanks to immigration, (that is to say, female carers from outside the EU) into Europe, we are in a position to ease the impact of social welfare assistance and care for the elderly and those who live alone;
e. in the case of nursing homes, the increasing pressure of work on the support staff offering care to the elderly also highlights the work-related stress that care personnel (doctors, nurses and personnel skilled in providing personal care and hygiene services) are subjected to on a daily basis.

There are several possible remedies to combat urinary incontinence, the first of which is the **rehabilitation of the pelvic floor muscles:** effective in treating stress

incontinence and provides good results even in the case of urge incontinence. The intention is to restore proper muscular support in the perineal area. Moreover, in severe cases, the rehabilitation of the pelvic floor guarantees a better success rate for corrective surgery.

There are also various types of **drugs** which act on the **central nervous system**, increasing the tone of the urethral sphincter thereby limiting stress leakage during the day time, or on **local receptors**, increasing the threshold of the stimulus and reducing the symptoms of urge incontinence. In some European countries the drugs are dispensed free whilst in other countries they are supplied on prescription or for cash payment (as in the case of Italy).

Recourse to surgical procedures are adopted in the event that rehabilitation or pharmacological therapies have not achieved the desired benefits. The objective is to restore, at any rate, in the least invasive way possible, the correct anatomical relationships between the various **pelvic organs** by means of support techniques that often make use of prostheses fitted transvaginally benefiting the urethra, the bladder and the vagina, which entails a very short hospital stay (2 - 3 days).

Children experience nocturnal enuresis, which is the repeated voluntary or involuntary release of urine onto clothing or in bed, during a development phase in which bowel control should be achieved. Enuresis is diagnosed when an individual releases urine twice a week over a three-month period. Most children reach sphincter control during both the day and night at the age of 5 years. There is **primary enuresis** (whereby no sphincter control is achieved) or **secondary/regressive enuresis**, but about 90% of children suffer from primary enuresis. Secondary enuresis is diagnosed between 5 and 8 years of age. Again, there exist different remedies and it is important to consider several factors:

1. cooperate with the child in tackling the problem and reward the child when it does not wet the bed;
2. parents also have to remember that children need to urinate every night before going to sleep;
3. punishing and humiliating the child in front of friends and strangers are to be discouraged, especially if carried out with a loud voice and a menacing tone;
4. it is not necessary to repeatedly wake the child during the night;
5. you should let the child go to parties and if necessary also allow them to sleep at their friends, in which case, they should wear incontinence pants;
6. in special circumstances, it may be appropriate to see a good neurologist. It may also be useful for people of all ages and where possible to fill in a **bladder diary** which records the **approximate water intake,** the **times** at which urination occurred and the amount of **urine** passed each time as well as a timetable and the manner of

eventual **urinary leakage** over a period of 72 hours.

Child behavioural management techniques. Addressing enuresis from a behavioural standpoint certainly requires a slightly longer period of time in comparison to pharmacological intervention, but it allows for the learned behaviour to be **maintained over the long-term.** The aim of this intervention is to act on the child's behaviour by utilising an incentive system that directs the child towards the acquisition of the **desired behaviour** (appropriate toilet behaviour, self-control, independence and self-esteem) whilst eliminating the **undesired** behaviour (bed-wetting, feeling ashamed). This is accompanied by a continuous monitoring of the psychological state of the child and his/her emotional (anxiety, fear, feelings of shame) and motivational behaviour. Enuresis is an embarrassment for a child and imposes a limit on the choice of activities. Further problems may also burden the child in the guise of emotional issues related to shame and experiences of derision by peers, especially during school age, when almost always **the law of the jungle** prevails and, sooner or later, letting friends know that the child uses a private toilet or the fact that their mother comes to school/nursery to change the pad/nappy at a pre-set time is hardly constructive. Enuresis may create a difficult psychological atmosphere even within **family relationships**, especially in those families where several children wet the bed. It is therefore advisable to **also intervene at a psychological** level with both the family and the bed-wetting child before adulthood and before acquiring the wrong behaviour towards this issue and society.

As a final point, male urinary incontinence can be caused by surgery for prostate cancer, but often it is stress incontinence and it, too, can be resolved with minimally invasive surgical procedures that allow for the resolution of the problem with a high success rate; otherwise silicone condom external catheters, drip collectors or small pads may be used.

The last medical taboo - Incontinence is a widespread problem in industrialized countries and it is difficult to accurately assess the magnitude of the problem and the number of people affected. The inability, whether it is less or more serious, to urinate at a given time and place has a psychologically devastating social impact which greatly affects the **quality of life** of the person and his/her interpersonal relationships. Suffice it to say that the "*social, psychological, occupational, familial, physical, educational, sexual and economic*" elements are all affected. The social costs due to incontinence are difficult to quantify (whether stress incontinence or incontinence due to an overactive bladder) and may also occur in young people, especially women at work who, out of shame or fear of being identified, rely on emergency aids such as

feminine pads, unwittingly fuelling the "social taboo" that characterizes this disease. Often, at a psychological level, both reactive depression and loss of self-esteem come to the surface and are accompanied by apathy, sense of guilt and interpersonal denial. The feeling of a lack of control over bladder function and the very thought of the smell of urine seriously undermines the self-esteem of the person, who readily begins to believe that they are a burden to the family and society.

Conversely, nowadays, incontinence is a problem that can be dealt with and can almost always be resolved, freeing the individual, once and for all, from all the problems affecting the "**quality and duration of life"**. The crucial concern is to create the right conditions to open ourselves up psychologically and culturally to those around us, talking with our partner, with the family doctor, with specialists in the sector and local patients' associations, where adequate answers supplied by people who have experienced a similar situation can be found, providing encouragement and enabling the individual not to feel "isolated".

We have already stated that **today incontinence is underestimated and is seen as a second or third-rate condition. S**uffice it to say that the first response given by modern society is still the pad which, within clinical, pharmacological and rehabilitative circles it is labelled as the means to "combat **incontinence"**, the final means used to resolve the problem. However in present-day Europe, it is only in France that rehabilitation of the pelvic floor is offered as a standard practice (provided for by their National Health Service) a month following childbirth. In addition, only few professionals recommend postpartum rehabilitation (which is a crucial tool in preventing female incontinence). This is due to a number of causes, including social, economic, political and cultural reasons. Consequently, incontinence sufferers are often reluctant to get involved and establish local patients' associations with collective responsibility.

The **Rehabilitation Centres for the prevention and treatment of incontinence** are of vital importance for people suffering from incontinence, indeed, they are the appointed place where one's problems can be resolved avoiding the need to go from one hospital to another, from one department to another; the patient is referred to the individual specialist or to a team of specialists, i.e. a group of qualified personnel who will care for them. Such teams should include: urologists, urogynaecologists, coloproctologists, midwives, registered nurses, physiotherapists, geriatricians and psychologists. Unfortunately, in Europe, except for some local organisations, "**Incontinence Rehabilitation Centres**" are non-existent but they should be set up nationwide. The setting up of the "Centres", jointly with the presence of an

appropriate specialized team and the "allocation of specific medical equipment", would play an important part in the prevention, treatment and cure of the condition, providing a suitable solution to requirements and a drastic reduction in social and management costs, to the benefit of society.

Whenever necessary, **medical devices** are of vital importance and must be "quality" products; national health institutions should ensure freedom of choice in the selection of the most appropriate and comfortable aid according to skin type, hygiene and anatomical shape. In several European countries (in Italy, for example) we have, for a while now, witnessed "competitive tendering" under monopoly conditions for pads (at local, provincial and regional levels), without any consideration for the "**quality and comfort of the products supplied"**, as it is only "**free choice**" that determines the quality of medical devices and creates a "market competitiveness" aimed at researching the highest quality products manufactured at competitive prices. The use of inadequate pads with poor absorbency and "infrequent" pad changing, causes serious infections in the elderly and, although it is widely believed that children's skin is the most delicate in the world, in reality this is not the case, because in the latter stage of life, the elderly person's skin is drier, more fragile, more sensitive to light, and possesses a bright and uneven pigmentation, therefore requiring more attention than children's skin. This is in order to avoid "**dermatitis**" and "**bed sores**" that cause so much suffering (and incur costs). Professionals are well aware that the sores are caused by prolonged pressure on body parts in direct contact with the skeleton, with a subsequent alteration of the localised blood circulation and damage to the skin tissue resulting in ischemia and skin necrosis (bed sores). **Bed sores** are caused by **perspiration and moisture in particular**, so it is good practice to maintain proper skin hygiene standards using non-acidic products. Other recommendations to combat bed sores are:

a. **never rub** the skin dry, dab it instead;
b. in the event of incontinence, change the pad frequently;
c. change damp or wet underwear/bed linen (due to perspiration or urine) regularly;
d. change the position of the patient every two hours, ensuring that any areas already affected are not compressed;
e. massage with care the areas most affected by skin ulcers;
f. do not use heavy blankets;
g. use air and water mattresses for bed sores and, possibly, a tilting or electric bed remembering that**, in all circumstances, the patient should be turned every 2 hours**. In order not to forget this point, a timer with an acoustic signal is recommended;
h. inspect the areas around the bones most at risk to pressure sores daily;

i. in the event of dry skin, the application of protective oils, emollients and moisturizers are invaluable for keeping the skin intact;
j. there are very effective products to combat bed sores on the market, although it is advisable to consult a specialist prior to using them.

With reference, once again to medical devices, it is important to point out that the Patients' Associations **have never had** "**any prejudice"** against pads and their producers. On the contrary, **quality products at competitive prices are most welcome**, but it is our moral obligation to reiterate that the pad **should not be regarded as the first response to incontinence,** but **as the last "resort"**.
A good quality pad must have the following features:
1. be a quality product;
2. be breathable;
3. be of a "belt all-in-one" type;
4. have skin-protective properties;
5. be of a "pull-up" type.

In several European countries, pads are available free from the National Health Service, and in some countries (such as France, for example) the cost is reimbursed by insurance companies; in other countries pads are paid for and the taxes are 4% (in Italy, for example) whilst in others they are 20% (in Romania, as an example). It must be pointed out that, in order not to be labelled as "incontinent", many people often purchase pads out of their own pockets and there are many women who prefer to use feminine pads for what they regard as "minor leakage". However, in reality, no taxes should be levied on pads, catheters, urine collection bags and other medical aids as they should be considered as "vital" products for the "survival and comfort of the individual".

Another factor not to be underestimated is that pads, nappies and feminine pads are difficult to dispose of and cause e**nvironmental pollution**; it is not a coincidence that some families, for a while now, have used washable (and, therefore, reusable) nappies (children), and pads (adults). However, high "costs" and lack of reimbursement measures from the individual Health Services now discourage this choice.

Incontinence and the Environment - Only 1.1 billion people worldwide are connected to a sewerage system, which means that the remainder of the population "perform" directly into the environment, with heavy environmental repercussions. On the other hand, it would be desirable for the world's inhabitants to build communal

latrines in those countries or regions where houses (or huts) have not been equipped with private toilets, or to implement education programmes for the population to highlight the link between hygiene and disease, as it is not always apparent even to those who actually own a toilet. The talk of toilets to people living in the "developed" world may raise a smile, but worldwide there are **2.6 billion people without toilets** and this creates many health problems as well as pollution. The provision of safe places where bodily functions can be performed would signify a dramatic reduction in water contamination and the spread of disease. In the ***third millennium, we must convince ourselves that we are all tenants of planet earth, and therefore we must respect our home.***

Toilets are humble but indispensable facilities without which no human being should have to perform their bodily functions. For incontinence sufferers, the lack of toilets in a country constitutes true social and 'architectural' barriers that severely limits, over a period of time, people's "personal freedom" and their movements; incontinence sufferers see this right denied to them which means that, to all intents and purposes, they are under **house arrest**; it is not a coincidence that when a person is in a theatre, at the cinema or on a plane, they prefer sitting next to the "aisle" in order to **quickly** dash to the toilet causing the least disruption to other people. Toilets are divided into two categories: public and private. Public toilets are located in bars, cinemas, theatres, airports, hotels, pubs, train stations, ferry terminals, etc. Private bathrooms are located in homes and workplaces. In short, public and private toilets are an essential requirement for human beings. The issues relating to public toilets are:

1. there are few - both within and outside of the town/city boundaries;
2. they are not well signed;
3. they are often dirty, narrow, smelly and poorly lit;
4. in a private home only having one toilet is often inadequate, therefore, where possible, one should go and live in (or build) homes with two toilets;
5. toilets in public establishments (*author's note: mainly in bars*) are often used for storage;
6. several public toilets only open during business hours - which is unthinkable for the elderly, children and women;
7. women are often charged to use them whilst they are free for men (this is a serious act of discrimination);
8. if you use a public toilet (in bars, pubs or restaurants) a purchase is almost obligatory to obtain the key to the door, otherwise one may be told that the toilet is "out of use";
9. even today, despite different national laws on toilet accessibility in public places

and at work, facilities are not always in accordance with regulations and **without "architectural barriers"**;
10. regarding the construction of toilets in public places, homes and workplaces, the European Union is recommended to take into account the legislation of the 27 member states and to produce an "ad hoc directive" valid throughout the whole of Europe.

Under these circumstances, one would understand very well that "a toilet complying with current regulations is worth its weight in gold"; indeed, it is very rare for municipalities, including art cities, to point out the location of public toilets and print city maps detailing a street plan, opening hours and entrance fees. The **World Federation of Incontinent Patients - WFIP** would encourage fee-paying, but manned, public toilets (*author's note: where they are manned, personnel almost always receive a small tip as well*). This choice of policy from the International Federation of patients would resolve a number of important issues:
a. public toilets would be cleaner;
b. public toilets would be safer, especially in the late evening and at set times;
c. public toilets would provide job opportunities locally thanks to the recruitment of attendants.

Incontinence and work are a difficult combination because it is not easy to have to leave one's work several times a day to "go for a pee". Think of a taxi driver, a clerk at a counter, a waiter, a sales-clerk, a business executive who are forced, on a number of occasions, to abandon their tasks/meetings to go to the toilet, etc. The employer's first suspicion is that this person is a slacker, somebody who goes to the toilet 10 times during the working day in order to waste time, a skiver who deserves instant dismissal. All these issues are not easily solved and are psychologically complex; trade unions at every organizational level must begin to take responsibility for these issues too. In the great majority of cases, today the Collective Labour Agreements in each European country provide for the protection of persons with disabilities, including cancer patients. However, there is no notion of tangible, visible physical disability within the **"World of incontinence"**, but there are almost always cases of job losses and, in the best-case scenario, a job change. Certainly, in order for the trade unions to intervene, the personal barrier due to incontinence must first be broken down; an individual has then to be open to dialogue and raise awareness among trade union leaders to solve these problems. The National Patients' Associations not only can, but must act, accordingly.

Incontinence and sports. Incontinence may be caused by an exertion made and, in this case, all it takes is just a laugh, a cough or minimal pressure on the abdomen to

cause a few drops of urine to be leaked. Any sport activity practiced with "***ultra restraint and, above all, planned***" is good for the human body. The more appropriate physical activities to prevent the onset of incontinence include stretching, gymnastic exercises to train the muscles of the pelvic floor, exercises carried out with light weights (*in sitting, supine and prone positions on a bench*), long walks, cycling, swimming, etc.. Whoever decides to practice swimming may do so by paying particular attention to the fact that often the water in the pool contains a chemical reagent which turns the water a purple colour when it comes into contact with urine. In short, any **physical activity may be practiced provided that it is useful in reinforcing the pelvic area.** The sports to avoid are those that involve violent physical effort (for example: weightlifting, shot putting, Greco-roman wrestling, judo, etc.); the important point is "**not to improvise"** and, within a short period of time, you will see for yourself which exercises are appropriate and which are not. In any case, it would be advisable to be guided by and plan a physical activity programme with a qualified trainer.

Sexual matters are of vital importance for all living beings, but more so for people who suffer from incontinence, as in the case of women, who may reach the stage when they refuse sex with their partners. After all, this is easily understood: it is unpleasant to see a woman urinating while having sex. The situation is embarrassing and it could make the woman blame herself up to the point where she withdraws into her shell, refusing contact with other people, in particular her partner. A man who has been operated on for prostate cancer can also have sexual problems, such as erectile dysfunction and retrograde ejaculation, but in both cases the problems can probably be resolved, as long as one discusses the issue with their family doctor and seeks a qualified specialist.

We have discussed the **psychological aspects**: the fear of leaving home and not finding a toilet, the horrible feeling that the pad is visible externally (especially in the summer) and that the skirt can get wet, the fear of producing bad smells (especially in the summer), the fear of confiding in one's family doctor, the sex denied and forgotten, the fear of receiving specialist incontinence problem related magazines at home (*author's note: without any privacy*) etc. These issues are, nowadays, easily solved if appropriate media campaigns are launched (press and television) against prejudice, which gives rise to the social and cultural isolation of the incontinent individual. It is worth mentioning that, after the war, only a few people dared to utter the word "cancer" and, moreover, say: "I have cancer." Today, thanks to the numerous media campaigns encouraged by National Patients' Associations, scientific organisations and national governments, cancer patients in Europe have eradicated

this way of thinking and behaving. The same 'techniques' should be adopted to overcome the "incontinence" taboo, but in order to achieve this aim, it is vital for all parties to work together in synergy.

T**he role of patients' associations**.
In terms of healthcare and patient care, the **World Federation of Incontinent Patients (WFIP**) and its affiliated national associations, are convinced that voluntary patient associations form a binding social force, not to be underestimated and that dialogue with political and economic organizations, health professionals, patients and the public as well as the media is vital. Indeed, the increasing role that people have in the control of social-health services and promotion of national and regional ad hoc legislation is of crucial significance. In several European countries, for over a decade, field studies have been undertaken in order to identify the indicators upon which the patients judge the skills of the health professionals, the pharmaceutical companies, the health and social policies of national governments. Within both national and European organisational processes, the role of the "**competent and informed patient**" assumes considerable importance and serves to outline guidelines which everyone must apply in the near future. The "**competent**" patient is one who has the confidence, skills, information and knowledge to play a central and decision-making role in the management of his own life, as the carrier of either a chronic disease or disability. It is no coincidence that the alliance between patients, health professionals and institutions has helped in the development of plans and guidelines to keep up with the times. Another vital role assumed by the patients' associations is the establishment of help-lines (especially during August and the holiday periods), which are most useful not only for incontinence-related issues, but for **loneliness**-related problems that often affect the majority of elderly people.

The "**World Continence Week**" was launched by the ICS (International Continence Society) in 2009 and is a major international showcase to raise awareness and bring out into the open (with the Population, Institutions and the Mass Media) the **incontinence problem**. The "**World Continence Week**" is held annually **during the last week of June,** whilst in Italy the "**National Continence Day**" was launched in 2006 and is held annually on **28th June**. Italy was the first nation in the world to request and obtain **political recognition of the "Day"** from its own government, thanks to a **Directive from the President of the Council of Ministers,** which allows for the "**National Day for prevention and treatment of incontinence**" to take place every year on 28th June. On this day, public and private health facilities participating in the initiative open their department of urology or gynaecology to the local population where the professionals carry out free check-ups on those who book a

medical examination. The task of coordinating the "**Day**" has been delegated to the **FINCO** Patients' Association - the **Italian Federation of Incontinent Patients**. The "Day" is sponsored by the **Ministry of Health,** the **Ministry of Labour and Social Policies** and the major Italian scientific organisations (both medical and nursing). In several Italian cities, in town squares and hospitals information desks are set up to provide details on incontinence, the FINCO accredited Rehabilitation Centres and the mission and goals of FINCO.

In conclusion, the scope of this document is to move towards a deep and meaningful consideration of the problems and strategies that we need to adopt in order to improve the **quality and duration of life of incontinence sufferers**.

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