Bladder and bowel control problems: Common but invisible disabilities

How business, leisure, transport and other premises can help
Bladder and bowel control problems are common. Anyone can be affected, male or female, young or old. Research from around the world suggests that between 19% and 33% of adult men and women have some bladder control problems, and between 5% and 8% bowel control problems.

Any problem controlling the bladder or bowel can have a serious impact on an individual’s day-to-day activities. This is especially true if the facilities they need to manage their condition are not available.

Many people use disposable products of various kinds to manage their bladder and bowel control problems, and when they leave home they depend upon access to facilities where they can change and dispose of these hygienically. Many report that they will only undertake trips away from home if they are certain about the availability of adequate toilet facilities, and that they avoid trips if they are uncertain.

The purpose of this short report is to raise awareness and understanding of the needs of people affected by such problems and to highlight how business, leisure, transport and other premises can help.
What are incontinence and other bladder and bowel control problems?

When we think of a bladder control problem, we normally think of urinary incontinence, which is the medical term used for involuntary leakage of urine. Some people have good bladder control most of the time, but occasionally experience a sudden leakage of a relatively small amount of urine – for example, when they cough or laugh or lift objects. Other people are unable to control their bladder for various reasons and a large amount of urine can leak suddenly, or the leakage may be slow but almost continuous.

Another troublesome symptom is known as urinary urgency, which is often associated with a condition called overactive bladder. People affected experience a sudden need to go to the bathroom, and sometimes may not make it on time. A less well known bladder control problem, which can exist separately or alongside urinary incontinence, is urinary retention, which means that the person affected is unable to empty their bladder fully, or at all.1,2

Faecal incontinence is the term used for an inability to fully control the bowel, resulting in leakage of stool. As with urinary incontinence, the leakage can be small or large.1,2

Also of relevance to this report are those who have had surgery for various reasons and now have a stoma. This means that their urine or faeces is diverted to a hole in their abdomen and collected in disposable ostomy bags or pouches that must be changed periodically.4,5

Many people of all ages are affected by incontinence and other bladder and bowel control problems. They do not affect only the elderly or people with other disabilities. Many active young or middle-aged people with no noticeable health problem or disability have bladder and bowel control problems.

Common reasons for urinary incontinence include multiple or difficult childbirths, prostate conditions, diabetes and obesity. Bladder and bowel control problems can also be caused by conditions such as multiple sclerosis and spina bifida, inflammatory bowel disease and irritable bowel syndrome, spinal cord and other injuries, dementia, certain treatments for cancer, and reduced mobility due to illness, injury or old age. Sometimes there is no known cause. For some the problems may be temporary, but for many others the problems are long-lasting.

Common causes of urinary incontinence include childbirth, prostate conditions, diabetes and obesity.
How common are incontinence and other bladder and bowel control problems?

With so many potential reasons for incontinence and other bladder and bowel control problems, it is no surprise that they are very common. Most research suggests between 25% and 45% of women and about half as many men experience some degree of urinary incontinence, and it has been estimated that between 5% and 8% of adult men and women experience some degree of faecal incontinence.1

It is difficult to give exact figures for how many people are affected by incontinence, because it depends which section of a population we look at, and whether we mean regular or occasional incontinence. Some experience incontinence every day while others may leak less frequently. In general more women than men are affected by incontinence, and older people are more likely to be affected than younger people.1,6 Research from around the world has provided estimates of how common the problems are in different sections of the population.

It is reported that between 7% and 37% of younger women aged 20-39 years experience urinary incontinence sometimes, with some 6-7% being incontinent every day. These numbers increase with age. Between 31% and 48% of women aged 40-59 have some degree of urinary incontinence.

Aged 60 years or more, between 37% and 63% experience urinary incontinence sometimes and between 9% and 39% are affected daily. Around 10% of women of all ages report leakage at least weekly.1,6

While the proportion of men affected by urinary incontinence is lower than that of women, significant numbers are affected and the proportions increase with age. About 2% of men aged 20-39 years experience urinary incontinence sometimes. This rises to between 2% and 19% of men aged 40-59 and between 11% and 34% of men aged 65 years or older. Between 2% and 11% of men of all ages report daily leakage.1,6

Many studies suggest that between 10% and 20% of men and women have an overactive bladder, which can lead to urinary urgency and incontinence. Again, the condition is more common in women than men, and becomes more common with age.1

Faecal incontinence affects around 6% of women under 40 years of age, rising to 15% of women older than 65 years. Of men, 6% to 10% are affected, the rate increasing slightly with age.17

Around 1 in 500 people in the UK currently live with a stoma, while tens of thousands must empty their bladder artificially because of urinary retention.5
Managing incontinence and other bladder and bowel control problems

Many people use healthcare products of various kinds to manage their bladder or bowel control problems.

For urinary incontinence, many people use disposable absorbent pads. The type and size of pad used depends on how much and how often the user leaks urine. Some are quite small and are worn inside normal underwear: for women there are pads that resemble normal sanitary towels, while for men there are pouch shaped pads. For more severe urinary incontinence there are all-in-one disposable briefs that can be used by both men and women. All these products are changed when wet, with the used product being disposed of and replaced with a new one. For most people these are the most familiar incontinence products, as they are becoming more commonly available in supermarkets and advertised in mainstream media.

But there are other urinary products that are less well known. Some men with urinary incontinence wear a condom-like product that collects leaked urine, which drains through a tube into a bag that is usually worn on the leg and is emptied as needed. Both men and women may have a catheter fitted - a thin tube that continuously drains urine directly from the bladder into a similar collection bag.

Many people who are unable to empty their bladder use a technique called “intermittent catheterisation” to avoid having a catheter in place all the time. This involves passing a catheter into the bladder at intervals throughout the day so that the urine can be drained into a toilet or other container, after which the catheter is removed and disposed of. Some people do this as many as five times each day.

People with faecal incontinence may use disposable pads or garments to prevent soiling of their clothes, and some use plugs rather like tampons to prevent leakage. Again, these are disposed of and replaced as necessary.

There are many different kinds of bags and pouches for use by people with a stoma. Some are designed so that they can be worn for several days before changing, and must emptied of urine or faeces several times a day. Others are single-use and are removed and disposed of each time they are full, and replaced with a new one.

Up to 19% of men aged 40-49 experience urinary incontinence sometimes.
Suitability of public washroom facilities

As bladder and bowel control problems are so common, we may all know or meet people affected, however we may not be aware, because very often people are anxious to conceal the problem, even if that makes life more difficult. One woman interviewed in an academic study said, “...you’d be really embarrassed if people knew you had a bladder problem. I prefer to use thin pads and change regularly, which is a bit inconvenient but better than wearing a pad that was bulky and could be seen.” 6,7

Bladder and bowel problems are hidden disabilities that can have a devastating affect on people’s lives. They can affect a person’s confidence and the way they think about themselves. Practical concerns about how they will manage their problem when away from home can affect many restrict activities because of uncertainty about availability of toilets. 9,10

All of the bladder and bowel management products and methods described previously mean that the person using them will need privacy and space to change a disposable product, use a catheter or empty a collection bag. Users report difficulties doing so in many public toilet facilities, and especially in men’s toilets.

Discreet and hygienic disposal is essential for products that are discarded by people managing bladder and bowel control problems. While hygienic disposal facilities intended principally for menstrual products are normally available in women’s toilet facilities, in male facilities there is often no hygienic disposal bin at all; typically there may only be one open-topped bin in a common area, which is neither suitable hygienic or discreet. An Australian support group moderator highlighted the problem faced by men with urinary incontinence: “I spoke to a lady yesterday whose husband had just started using disposable incontinence pads. One of the things she was finding was that male public toilets ... often do not have rubbish bins, hence pad or bag disposal is problematic.” 11

In fact, research interviews and in online forums people frequently express frustration about difficulties in disposing of used products and the poor availability of suitable hygienic receptacles in men’s toilets. 12,13

A major report on products for bladder and bowel problems included interviews with product users at eleven focus groups, in which disposal in public places was a significant concern for all those taking part. Group discussions included comments about “the lack of facilities for disposal of penile sheaths and catheters in male public toilets, and the small size of disposal units for larger disposable incontinence pads.” 14

The availability of clean hand-washing facilities and hand sanitisers is also of importance to all of us, but especially so to those managing bladder and bowel control problems. People affected by incontinence report anxiety about poor availability of adequate hand-washing facilities when away from home. 15

Those who use intermittent catheterisation must be able to wash their hands before and after using a catheter to empty their bladder, so it is useful if hand-washing is possible within the toilet cubicle. The same is true for people who use ostomy bags. 16

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"Most loos across the UK don’t meet the requirements of ostomates. A sanitary bin and sink in the cubicle itself, as well as increased surface space, can make changing a bag significantly less difficult.” 15

Representative of the Colostomy Association writing in a leading British newspaper

"Male public toilets ... often do not have rubbish bins, hence pad or bag disposal is problematic.”
Changing requirements for toilet and waste disposal facilities

For several reasons the demand for facilities that are suitable for using and disposing of products for bladder and bowel control problems is likely to increase.

Increasing numbers of people affected by incontinence

It is likely that incontinence and other bladder and bowel control problems and consequently the use of products to manage them will become more common.

Worldwide, populations are ageing and more people than ever before are surviving serious illnesses that can lead to bladder and bowel control problems. Conditions such as diabetes and obesity, which can increase the risk of incontinence, are becoming more common.

In the United Kingdom the proportion of the population aged 20 years or older who were clinically obese (with a body mass index greater than 30 kg/m²) rose from 13.4% of men in 1990 to 24.5% in 2013, and from 16.2% to 25.4% of women.

In the United States in the same period the proportions rose from 19.9% to 31.7% of men and from 23.6% to 33.9% of women. It is estimated that the number of people in the UK with diabetes has more than doubled in two decades, from 1.4 million in 1996 to 3.3 million in 2015. In the US the National Health and Nutrition Examination Survey revealed that the proportion of women reporting some degree of urinary incontinence grew from 49.5% in 2001-2 to 53.4% in 2007-8, while in men the proportion grew from 11.5% to 15.1% in the same period.

In addition, there have been efforts to ensure that more people affected by incontinence seek appropriate help: it is estimated that currently only a quarter of people affected by urinary incontinence and a third by faecal incontinence consult a medical professional.

Consulting with health professionals leads not only to possible treatments but also to greater awareness and use of the products and methods that are available to manage bladder and bowel problems so they do not prevent those affected from living full lives.

Increasing popularity of disposable incontinence products

Adult incontinence products are the fastest growing retail disposable hygiene category globally. The sales of adult incontinence products are already set to outstrip infant diaper sales in some countries. The manufacturers of absorbent products are working to increase both the size and their share of the market.
In the UK alone the market size for adult incontinence products was estimated to be around 300 million sterling in 2015, and set to rise to 590 million in 2025. Product types that were once only available in pharmacies or medical supply stores are now available and highly visible in supermarkets and other high street outlets, and are advertised in the mainstream media. In the UK, the proportion of incontinence products purchased through retail outlets or online is now 35% and rising, while the proportion supplied by the National Health Service is decreasing.

In North America the retail volume of adult incontinence products grew 6% from 2015 to 2016, and it is estimated that there will be a compound annual growth rate in the market of 7.5%. The increased availability and visibility of products raises awareness that incontinence is common and reduces stigma around product purchase and use.

The expansion of markets for disposable bladder management products is not limited to absorbent goods. In England alone, costs to the NHS for intermittent catheters rose from around £13.5 million per annum in 1999 to £88 million in 2013, the bulk of this cost being for disposable single-use catheters. That means tens of millions of catheters and their packaging are being disposed of each year.

The use (and disposal) of ostomy products is similarly growing: in 2012 £228 million of ostomy bags and accessories were dispensed in England alone. The vast majority of these products are used by people living in the community who need to access public and workplace toilet facilities with suitable facilities for hygienic disposal.

Increasing awareness and changes in legislation

There is also likely to be an increase in demands for improved provision of toilet and sanitary disposal facilities from civil society and lawmakers. There is an increasing recognition that “invisible disabilities” such as bladder and bowel control problems have been largely ignored by provision to date. Several of the largest UK retailers have changed the signs on accessible toilets so that they include symbols depicting standing men and women as well as the familiar wheelchair user, along with the slogan “not every disability is visible.” However, although people with bladder and bowel control problems may be entitled to use accessible toilets that are more likely to have disposal facilities, many may not want to do so.
because it will draw unwanted attention.

The need for disposal facilities for personal hygiene products for both men’s and women’s toilets is currently poorly recognised in laws and regulations in most countries. As an example, in the UK premises are only required to provide appropriate disposal facilities in toilet facilities used by women.39

Workplace health and safety regulations specifically pertaining to the disposal of waste associated with bladder and bowel products only apply to settings where health care is being provided.40

However, this may be set to change, especially as use and awareness of bladder and bowel control products increases. Environmental law stipulates that the management of any premises have a duty of care that all waste produced on the premises is correctly managed to the point of final disposal.41 This means that owners or managers are ultimately responsible for the appropriate collection, handling and legal disposal of bladder and bowel management products disposed of on business, leisure, commercial, transport and entertainment premises.

Perhaps the simplest way to fulfil this obligation – and at the same time to meet the needs of customers and staff who use incontinence products – is to provide appropriate hygienic disposal receptacles in all toilet facilities. In Germany a law has already been passed in 2013 that recognises the need for hygienic disposal facilities in men’s toilets. It requires employers to provide a hygienic container with a lid for each toilet in women’s toilet facilities, and at least one such container within a marked and designated toilet compartment in men’s facilities.42

A German national prostate organisation and the German Hotel and Restaurant Association also campaigned for much wider provision of hygienic disposal bins in men’s toilet facilities.43 Around the world other organisations representing the interests of people affected by bladder and bowel problems have highlighted the poor availability and standards of toilet facilities, including the need for suitable waste disposal bins.44-47

Few people would disagree with improved provision of toilet and waste disposal facilities. Improvements that are essential for people with bladder and bowel control problems will also benefit everyone else.
In conclusion

- Bladder and bowel control problems are very common and affect men and women of all ages. Research from around the world suggests that between 19% and 33% of adult men and women have some bladder control problems, and between 5% and 8% bowel control problems.

- The number of people affected by bladder and bowel control problems will increase, as will the use of disposable health care products.

- In order to work, shop, travel or enjoy a social life, those affected rely upon the availability of facilities to manage their problems.

- Both men and women need facilities to hygienically dispose of the products they use.

- The lack of hygienic disposal facilities in men’s toilets and insufficient facilities in some women’s toilets are problems reported by researchers and patient groups.

- Recognition of the needs of people affected by invisible disabilities such as bladder and bowel control problems is increasing.

- Regulatory requirements for improved provision of waste disposal facilities may be extended. Environmental laws already stipulate that premises have a duty to ensure appropriate disposal of all waste. A law has already been passed in Germany requiring the provision of hygienic disposal facilities in men’s workplace toilets, and similar regulations may be adopted by other countries in the near future.

- The owners and managers of work, business, leisure, transport and other premises can make the lives of those affected by bladder and bowel problems easier by ensuring they have access to the facilities they need.

- Improvements in facilities that are essential to people with bladder and bowel problems will also benefit others.

The owners and managers of businesses can improve the lives of those affected by bladder and bowel problems by ensuring they have access to facilities they need.
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