

Taking Control of Incontinence



**Exploring the links
with social isolation**

Introduction

Incontinence is an issue frequently brought to the attention of Help the Aged via helpline calls and letters from the public, and at meetings with health professionals and older people.

Whether older people are facing difficulties in accessing their local continence service, the threatened closure of a local public toilet or restrictions on the number of incontinence pads given out by local healthcare providers, they report situations where their dignity is compromised and their quality of life diminished.

We wanted to find out more about how people cope with incontinence and what Help the Aged can do to make a difference. We undertook a number of research studies to find out more about the problems older people face.

Nowhere to Go: public toilet provision in the UK collates almost 1,000 people's comments and experiences of using public toilets. Many people say they are restricted in how often and for how long they are able to leave their homes because of the lack of public toilets.

Incontinence and Older People: is there a link to social isolation? (2007, Help the Aged) contains 20 interviews with people about the impact of incontinence on the quality of their life. What is revealed is that some people have an optimistic and courageous way of dealing with this difficult problem; others manage with the support of family and friends and through their participation in outside interests, while a small number regard their shrinking social involvement as permanent.

These reports, and evidence from other sources, suggest ways in which Help the Aged can work to make a difference to older people's lives. These are listed in a series of 'We will ...' statements towards the end of this booklet. We will also work with other voluntary organisations, clinicians and practitioners in a united bid to improve the continence care available for older people in the UK.

Fact and figures

Incontinence is not an inevitable part of ageing but the condition is more common in older age.

Being incontinent is second only to dementia as the reason why older people enter residential care

Good Practice in Continence Services, 2000, Department of Health

An estimated 6 million people suffer from incontinence

Talking Incontinence: understanding urinary incontinence, Research into Ageing fact sheet, 2005, Help the Aged

Fifteen per cent of older men and women over 65 living at home have faecal incontinence

www.continence-foundation.org.uk

About 50 per cent of all men will have an enlarged prostate by the age of 60, rising to 80 per cent in their 80s; this often causes incontinence

Talking Incontinence: understanding urinary incontinence, Research into Ageing fact sheet, 2005, Help the Aged

One-third of us develop incontinence at some point in our adult lives

Talking Incontinence: understanding urinary incontinence, Research into Ageing fact sheet, 2005, Help the Aged

Fifty-two per cent of respondents [to our survey] agree that the lack of public toilets in their area stops them from going out as often as they would like

Nowhere to Go, 2007, Help the Aged

Eighty per cent of respondents do not find it easy to find a public toilet

Nowhere to Go, 2007, Help the Aged

Seventy-seven per cent of older people agreed that there are not enough public toilets to help older people get out and about

RoAD ICM survey, 2006, Help the Aged

What is incontinence?

Incontinence is the accidental or involuntary leakage of urine or faeces. It is thought that at some time in our adult lives one in three of us will experience incontinence. We know urinary incontinence is more common in women and that the prevalence of faecal incontinence and double incontinence is about the same in both men and women. According to the Department of Health, being incontinent is second only to dementia as the reason why older people enter residential care.

Although an estimated 6 million people suffer from incontinence, this taboo subject is rarely discussed openly. While not an inevitable part of getting older, incontinence tends to increase as we age.

There are several types of incontinence. Faecal incontinence is the involuntary loss of faeces or wind. Stress incontinence is the involuntary escape of small amounts of urine when a person coughs or laughs. This is particularly common after childbirth when the muscles which close off the tube that passes urine may be stretched.

Other common problems include urgency – the pressing desire to pass urine, accompanied by an inability to control the bladder as it contracts involuntarily. Urgency may also arise from the inability to empty the bladder fully, normally because of obstructions such as an enlarged prostate. The urinary system depends on a complex system of monitoring

by the brain. Any accidental damage to the nerves involved, or a disease affecting the relevant parts of the brain or nervous system, can result in continence problems.

Incontinence affects personal hygiene and overall health, causing conditions such as pressure sores and urinary tract infections that can potentially be life-threatening. It is not just the physical side of incontinence that is distressing. It can also have psychological and social effects.



Coping with incontinence

There is limited research on how people cope with incontinence. Experts have tended to concentrate on why someone is incontinent rather than how it may affect their emotional well-being or participation in activities. Studies have tended to focus on urinary incontinence rather than faecal incontinence and most have concentrated on women.

To understand more, Help the Aged commissioned the BioMed Centre in Bristol to undertake a specific study on incontinence and isolation in collaboration with the Faculty of Health and Social Care, University of West England. This involved interviewing 20 people aged over 65 about the impact of the condition on their behaviour, psychological and social health and the potential link with social isolation. Eleven people also completed diaries.

During the interviews, five men and 15 women discussed how they felt about incontinence, explained their beliefs about the causes and talked about what being incontinent meant to them. They also mentioned a number of ways in which they coped and managed their condition, and described how they maintained a sense of well-being and self-esteem.

In summary, the findings reveal that older people strive to make sense of their incontinence and use a wide repertoire of coping and managing skills. The findings also give insight into the complex ways in which incontinence may impact on social isolation, activity and well-being.

Making sense of incontinence

Although people were not asked to explain the causes of their incontinence, many of the respondents did offer some explanation, reflecting a desire to make sense of their condition.

'I mean I did say to this lady down the clinic, I said, "I went to bed the other night," I said, "and I got up four times and I could not believe the amount. It wasn't just a trickle.' '

Even though the association with ageing is recognised as a common perception, it does not necessarily accord with the respondents' own beliefs:

'Well, what I meant was, I think men don't realise. They think this is something that comes with old age. I've just got to put up with it and other people have got to put up with it. It's not bad but there it is and, no, I think it's very sensible to do what I did, or what my doctor said. There's this specialist nurse who knows all about these things and may be able to help you, which indeed I think she is.'

Some of the respondents seem to feel responsible and blame themselves for their condition or link it to life events, such as the death of relatives, moving house or retiring.

'Course, they tell you to do these exercises and stupidly I didn't keep it up. I don't know why I didn't.'

'I did not seem to have much of a problem then. It seems to be worse since he died... I don't know why that is... I know it's got worse in the last eight years since he died.'

People vary greatly in their openness and willingness to confront their incontinence in the first place and subsequently discuss their condition with others, but all affirm that incontinence continues to be a taboo subject.

'It's just that this problem ... [pause] ... it isn't a thing you talk about, is it?... I'm a bit... I – I'm embarrassed, that's what... you see. I get embarrassed if I get to talk to people about it... because I think it's, well, it's not a very nice thing to talk about, is it?'

Some respondents seem to cope by saying that incontinence is not much of a problem at all.

'When at home I live in my underpants unless I'm expecting visitors. It allows me those extra few seconds to reach the toilet. I'm so used to it, I take no particular notice now.'

'I mean I don't talk about any other of my problems. I'm not that type of person. I just get on with it. I think there are other people far worse than me, with other illnesses and things you know.'

Older people use different ways to keep control over their bladder and bowels and to maintain dignity in public. They include practical actions to cope with the uncontrolled flow of urine or faeces and psychological

strategies, which enable the older person to redefine what is 'normal' in terms of control over their bladder and bowels.

All interviewees have ways to conceal their incontinence. Even those who are more open about their problem are discreet in their management of it, carrying spare pads in a rucksack or unobtrusive bag, for example. All said they only discuss the issue with a few people. One interviewee reported not telling her husband she has faecal incontinence despite having had major operations. However, she does talk frankly to one very close friend.

Others said that having someone to talk to about their incontinence helps them to cope, both in avoiding potential embarrassment and in coming to terms with incontinence. Often talking about incontinence reveals that others share the problem and this makes them feel 'more normal'. However, opportunities for discussion in people's immediate circle of family and friends can be constrained by their embarrassment.

People invest time and effort to make sure they are prepared to cope with their incontinence at home and when they venture out of the house. Making sure they are equipped to go out becomes an integral part of life and allows them to engage in activities outside home.

'I've had some accidents. I change the pads to make sure. It's about management. You learn how to calculate. It's not the chore it sounds.'

'Well – em – I mean, it is embarrassing. I mean I wouldn't go out without a spare pair of pants and a pad in my handbag, you know.'

The degree to which dignity is compromised when suitable facilities do not exist are illustrated by the quote below. Many of the older people are forced to resort to buckets, jars and jugs in order to avoid an accident in public or in the privacy of their own homes. They resort to anything that works for them.

'I got the jar to carry around with me, not so much now I'm on these tablets. But if I go from here to Bath, I go to the toilet before I go and by the time I get to Bath I want to go again. But the toilets are locked. The first two toilets I pass are locked so then we have to park up and I got me bottle and I have to sit in the car which – there's no other way of doing it, you know. Do it in a jar and then I can pour it out.'



For many older people, it is vital to know exactly where the toilets are in the areas they frequent. For many it is the first consideration in planning an activity and can be a deciding factor in choosing where to go.

'And I like to go to places where I know where the toilets are. And I always say to her when we get somewhere, "Let's go and have a cup of coffee first," 'cause I know that wherever we go for a cup of coffee

or a cup of tea, there'll be a loo. So that before we start doing anything I can go to the loo.'

'I don't mind going out so much when I know where the toilets are. And I can shop when I'm about near the toilets – that's not too bad.'

Keeping control

Not letting incontinence dominate their lives is important for many interviewees. They strive to keep control over their bodies and also their minds. Several spoke about 'mind over matter' and commented on the importance of not letting thoughts about incontinence and its management become all-encompassing. This strategy of taking control is an important way of coping.

'It doesn't dominate my thinking all the time.'

'We get on with it. What's the alternative? If you get depressed or despondent about it and then you let it get you down, it's the tail wagging the dog.'

One way in which some respondents keep control over their incontinence is to remain engaged in activities. Many recognise the importance of going out.

'I do try and make myself go out. I'm going out tomorrow morning. I'm using Dial-a-ride to take me shopping, which is a very good service, so I can do my own shopping and if I want to go up to the precinct...'

How public toilets are failing older people

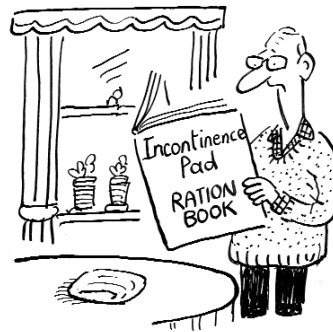
There is little doubt that as we get older we may need to use the toilet more often and with greater urgency. This means that when we leave home we depend on the availability and accessibility of public toilets, whether provided by local authorities or local businesses and companies. However, the 2007 Help the Aged research report *Too Old: older people's accounts of discrimination, exclusion and rejection* found that 77 per cent of older people agreed that there are not enough public toilets to help older people get out and about. Evidence from the *Spotlight Survey 2007* found that of the people who said they did not lead as full and active a life as they would like, 11 per cent (over 1 million) said that they would be more active if there were more public toilets.

It is not only a lack of public toilets that is the problem, but also the poor quality of provision. The Help the Aged report *Nowhere to Go*, which summarises older people's views on public toilet provision in their local area, found that the lack of accessible public toilets is a major concern for many older people:

- 80 per cent of respondents do not find it easy to find a public toilet.
- 78 per cent of respondents find that their local public toilets are not open when they need them.
- 79 per cent of respondents find that safety concerns make public toilets unappealing.

Both this survey and other Help the Aged investigations have found that the issue of hygiene and cleanliness is also a vital one for older people. In one study, people said they faced a dilemma between their need for a cubicle for privacy 'and the sitting facility', and the risk of infection because the toilet area was unclean. Public toilets need to have clean floors, seats and walls if the public are to use them safely.

Taking responsibility for the improvement of their incontinence is an important way to keep control. People are generally avid for advice from professionals, especially continence advisers, about what they can do to aid their own recovery or manage their incontinence more effectively. Following professional advice by doing pelvic floor exercises regularly and keeping to any recommended drinking or diet are part of the self-help regime.



'Well, I suppose it's sort of go on, try and persevere to do what they tell you. Because, I mean, they tell you that doing these floor exercises, pelvic floor exercises, it does take at least three months or even more, you know, to get a real effect and the lady I saw yesterday, she said I was doing them really well... Well, how to control it, isn't it, that's the main thing? I mean, when once you've got control of it and you know [how to do it], life would be so much different.'

Imposing restrictions

Interviewees restrict their lives in order to avoid accidents, ranging from rationing drinks and pads to restricting the time spent away from home.

'I got to keep running to the loo all the time and I wish, I wish that I could get out more but I'm afraid to go too far, although if I want to go any more now I got to take a taxi. 'Cos there's a lane where that lorry is, that goes out to [place] and the bus stop is at the top of [place], but if I have to stand there for long I don't think I could do it.'

Many interviewees drew attention to the expense of pads. Some have a limited number of pads supplied to them or have a special allowance for decreased mobility.

'As soon as I'm on my feet it's like I keep changing, so what I would do is cut up pads and put extra lining in the proper pad. That's not very comfortable.'

'I have the [brand name] pads and of course they're very expensive. I mean they're about, they're almost £7 for 12 and I use about... sometimes I've used three a day but I've got down to about two, you know. I mean fortunately I do get Attendance Allowance because of my not getting about, so that helps quite a bit, obviously, otherwise I don't think I could afford to do it. But then they've never offered me any. I did ask at the surgery, you know, if I could get any pads and no, they didn't supply.'

In many older people's experience, physical activity makes incontinence worse. Bending down to tie a shoe lace or turning over in bed can aggravate the incontinence. Many participants reported that stairs are a problem since going up or down prompted voiding. For some, only slightly more strenuous actions, such as walking, pushing a trolley or lifting laundry, aggravates their incontinence.

For some older people, the difficulty in using public transport where facilities are poor or not provided is so great that it is not a travel option.

'I thought, "I've been in this pad all day yesterday and all night. I've now got to go and change," but I couldn't go on the toilet on the bus, you see. There was a toilet on the bus but I couldn't go in it because I didn't know whether they'd have a tin in there where I could put me used pad. And I'm very funny – that's one thing I don't like. That's the only thing that gets me, is if I go somewhere I got to make sure they got somewhere for me to put me used pad. And sort of put it in a bag or something and put it in there to get rid of the smell and that...'

Incontinence and isolation

The findings from *Incontinence and Older People: is there a link to social isolation?* suggest that incontinence has the potential to contribute to social isolation. However, many issues are linked to social isolation, such as increasing age, living alone, restricted social network, life events and ill-health.

Generally, there are three ways in which people cope:

- A small minority of older people dwell on their shrinking social interaction and seem to regard it as permanent.

- A majority of older people feel there are circumstances which make them afraid to go out because their symptoms seem so severe and beyond their control.
- One group shows determination to carry on with life as normally as possible and achieved this by employing a range of strategies to manage their incontinence.



Three factors that influence to what extent people cope are:

- a personal attitude that refuses to allow incontinence to defeat the person experiencing it;
- the quality of support from family or friends; and
- the presence or absence of compelling interests.

As well as personal issues, which may link incontinence with social isolation, older people reported environmental and contextual factors which are important, including:

- public awareness of incontinence and access to information;
- quality and availability of toilets;
- personal finances;
- professional support; and
- transport provision.

Public awareness of incontinence and access to information

Help the Aged is committed to ending the conspiracy of silence on the subject of incontinence.

We will:

- raise awareness of the impact of incontinence on people's lives by bringing the subject into the open and breaking the taboo;

- encourage older people who are experiencing incontinence to seek help and advice from health professionals, because in many cases incontinence can be cured or improved; and
- encourage a co-ordinated local approach to the provision of comprehensive and localised information – for example, maps of local toilets.

Quality and availability of toilets

Help the Aged is committed to ensuring that toilets facilities are readily available, accessible and well maintained.

We will:

- encourage local authorities to prioritise the provision of public toilets and to set it as a best-value performance indicator.
- recommend that the Government commits to commissioning a regular national mapping exercise to ascertain where toilet facilities are declining. This exercise used to be undertaken by the Audit Commission. Since it stopped, campaigners report that the level of provision has plummeted.
- encourage the provision of accessible and well-designed toilets with adequate numbers of cubicles, hand-washing and disposal facilities which are cleaned regularly and well-maintained.
- encourage hospital trusts to provide a high standard of toilets and toileting facilities on wards and involve older people in monitoring standards.

Personal finances

Help the Aged is committed to ensuring that older people have the resources they need to deal with their incontinence. This equipment should be of good quality, affordable and readily available.

We will:

- call on primary care trusts to ensure that everyone who needs incontinence pads has access to an adequate supply of well-designed pads.

- urge manufacturers, retail and supply chains to produce and market affordable and well-designed pads; and
- campaign to tackle pensioner poverty.

Professional support

Help the Aged is committed to providing information about incontinence to those working with older people.

We will:

- support the development of best practice in continence services by disseminating information and research; and
- raise awareness among those who work with older people of the impact of incontinence on older people's lives and how incontinence is not inevitable in older age.

Transport provision

Help the Aged is committed to ensuring a high standard of public transport which provides appropriate and sufficient toilets.

We will:

- call for safe, accessible, reliable and affordable public transport which enables all older people to use it; and
- encourage the provision of adequate, accessible, well-maintained and equipped toilets with the necessary disposal facilities for pads at all bus, coach and railway stations and in facilities on coaches and trains.

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Other incontinence work

Biomedical research

Research into Ageing is a biomedical research programme within Help the Aged. Founded in 1976, it funds research into the most common illnesses affecting older people, such as incontinence. Current research projects include tackling infections caused by catheters, examining changes to cells in the bladder that trigger contractions and bladder-voiding, and the role of exercise in improving incontinence. A useful fact sheet, *Talking Incontinence: understanding urinary incontinence*, is available free of charge from www.ageing.org

Campaign work

Behind Closed Doors: using the toilet in private is a dignity campaign led by the British Geriatrics Society, Help the Aged and other organisations. It aims to improve standards of toilets and toileting on the ward in hospitals. More information is available at www.bgs.org.uk/campaigns/dignity.htm

Relevant publications

Bladder and Bowel Weakness: managing incontinence is a free Help the Aged advice leaflet available from 020 7278 1114 or www.helptheaged.org.uk

Incontinence and Older People: is there a link to social isolation? is available to download at <http://policy.helptheaged.org.uk/healthyageing>

Nowhere to Go: public toilet provision in the UK is available to download at <http://policy.helptheaged.org.uk/healthyageing>

Too Old: older people's accounts of discrimination, exclusion and rejection can be ordered from Help the Aged Publishing for £15 (plus £1.75 p&p) on 020 7239 1946

The Spotlight survey was conducted by GfK/NOP in January 2007 for Help the Aged. The *Spotlight Report 2007* was published in May 2007 and can be ordered from Help the Aged Publishing for £6 (plus £1.75 p&p) on 020 7239 1946

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WE WILL fight to free disadvantaged older people in the UK
and overseas from **poverty, isolation and neglect**

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