



February 2008

Key Points:

- Replaces previous version dated February 2007
- How to access help with continence problems
- Organisations that can provide advice and support

Help with continence

The information in this factsheet is aimed at people aged 60 or over.

As different rules may apply, those living in Scotland, Wales or Northern Ireland should contact:

Age Concern Scotland,
Causewayside House, 160
Causewayside, Edinburgh, EH9
1PR, tel: 0845 125 9732 (lo-call
rate), Monday to Friday, 10am to
4pm, website:
www.ageconcernscotland.org.uk;

Age Concern Cymru, Ty John
Pathy, Units 13/14 Neptune
Court, Vanguard Way, Cardiff
CF24 5PJ, tel: 029 2043 1555
(national call rate); website:
www.accymru.org.uk;

Age Concern Northern Ireland,
3 Lower Crescent, Belfast BT7
1NR, tel: 028 9032 5055
(national call rate) Monday to
Friday 9.30am - 1pm, website:
www.ageconcernni.org

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1. Why you should seek help

Incontinence - that is loss of bladder or bowel control - has many causes. It can affect men and women but is more common in women. It is not a 'normal' part of ageing, although it may be more likely as people grow older. In many cases, especially if diagnosed at an early stage, there will be effective treatment that can help to manage or cure the problem. This is true no matter how old the person is. That is why it is important to find out why you, or the person you look after, have a problem.

This factsheet aims to help you understand a little about incontinence and to suggest where to find further help and information.

2. Different ways in which incontinence may affect you

Incontinence can be a difficult thing to talk about. It can present practical, emotional and personal hygiene difficulties. It can also cause skin irritation and soreness if not managed effectively. All these things can significantly affect an individual's quality of life. Therefore if you or someone you care for has a problem, always speak to your GP or someone at the local continence service about it.

The types of incontinence and some of the more common causes and treatments are described below.

2.1 Incontinence of the bladder

Stress urinary incontinence

This is the most common type of urinary incontinence. In this case muscle weakness can cause leaking of urine when you laugh, sneeze, cough or take exercise. The weakness is not of the bladder itself but of the 'pelvic floor muscles' surrounding the base of the bladder. There are special exercises you can do to strengthen these muscles. You can find out more about these exercises by talking to a specialist health professional or from publications produced by the organisations listed in Section 7.

Urge urinary incontinence

In this case there is a sudden strong desire to pass urine which cannot be ignored. Normally as your bladder fills, your brain gives you plenty of warning so that you can reach the toilet in time.

In some people this does not happen. Muscles in the bladder contract more often than normal and with little warning, causing leakage of urine. It may be accompanied by the need to pass urine frequently - maybe every half an hour - which is known as 'frequency'.

These symptoms can also be due to a urinary infection. If so, they may respond to antibiotics. If not, you may be advised to try what is called 'bladder retraining'. Here the aim is to teach you techniques that allow you to ignore the urge to pass urine. This should help you return to a more normal pattern of no more than six to eight times a day. Help from a health professional is usually needed to learn the techniques (see Section 3). Publications from specialist organisations may also help. See Section 7.

Nocturia

This tends to affect older people more than younger adults and is more usual in those over 60. It means being woken up at least twice during the night to pass urine. If your sleep is regularly disturbed, it may leave you feeling constantly tired during the day. If this is the case, see your GP or contact your local continence service directly to discuss it.

If you need to go to the toilet during the night, ensure the route is well lit or keep a torch by the bed. Also check the route and ensure there are no hazards such as shoes on the floor or furniture to negotiate that might cause you to trip or fall. If you could be in danger of falling, you may find it helpful to consider a commode in the bedroom.

Leaking

This may only happen occasionally but it can still be a worry. In men it may be caused by changes in the prostate gland. Problems may also arise if you regularly suffer from constipation. Constipation can put pressure on the bladder, which then leads to leaking of urine. If this is the case, changing your diet may be suggested to treat the constipation.

Functional incontinence

Functional incontinence is due to practical difficulties such as:

- inability to remove clothes easily; *or*
- inability to reach the toilet in time due to walking difficulties or unnecessary obstructions such as awkwardly placed furniture.

If physical barriers are preventing you reaching the toilet in time, see what changes you can make.

2.2 Incontinence of the bowels

Loss of bowel control is also known as faecal incontinence. It can have a variety of causes, including damage to the muscles or to nerves supplying the muscles around the back passage. It can also be due to constipation even though the effects appear more like diarrhoea.

3. What help may be available

You should seek advice about any type of incontinence as early as possible.

Good practice in continence services was published by the Department of Health in April 2000. It outlines how continence services should be organised so that people have equal access to services whether they live at home, in a care home or are about to be discharged from hospital.

The *National Service Framework for Older People* (NSFOP), published in March 2001 emphasises the importance of integrated continence services and indicates what a quality service should look like.

A report was published in November 2005 following *the first national audit of incontinence care for older people in the UK*¹. The audit (which although national did not cover every PCT area and hospital) examined the quality of care for both urinary and faecal incontinence for those living in their own homes, in care homes and when in hospital.

It suggests that although there is a basic infrastructure in place to deliver improved services, there is inadequate assessment of patients with an emphasis on containment rather than cure. The authors suggest this indicates a missed opportunity to assess, treat and reduce the number of incontinent people.

Your local Primary Care Trust (PCT) will have a policy explaining eligibility criteria for the local continence service, including the provision of continence supplies and aids.

¹ National Audit of Continence Care for Older People Report of the National Audit of Continence Care for Older People (65 years and above) in England, Wales and Northern Ireland. The audit was commissioned by the Healthcare Commission and undertaken by the RCP Clinical Effectiveness Unit. [www.http://continenceaudit.rcplondon.ac.uk](http://continenceaudit.rcplondon.ac.uk)

Pads should not be made available without an assessment by a trained nurse or specialist adviser and should be provided in quantities appropriate to your needs. If you are assessed as needing continence pads and meet your local PCTs eligibility criteria, you should not be charged for the pads. PCT guidelines may stipulate the maximum number of items that may be issued per 24 hour period. Contact your local PCT Patient Advice and Liaison Service (PALS) for information about local eligibility criteria. Call NHS Direct on 0845 4647 (lo-call rate) for details of your local PCT PALS.

Continence services in the community operate under the guidance of a local continence service. This is staffed by specialist nurses - often called continence advisers - and sometimes specialist physiotherapists. Services across the country may operate in different ways.

In many parts of the country you can contact the local continence service directly without seeing your GP first. This is often referred to as an 'open access' service. To find details of your local service you could contact the Continence Foundation helpline or search their website for your local clinic. (See Section 7). Your local PCT PALS should also be able to tell you.

If you live in or are about to move to a care home refer to Section 5.

If it is suggested you have an assessment by a nurse who has received specialist training, the aim will be to identify your problem and a treatment that may help or cure it. It will be important to explain how the symptoms affect your day-to-day life. Your lifestyle, medication or pattern of daily fluid intake may have a role to play. The assessment process may include the keeping of a 'bladder diary' and/or a physical examination. As a result of the assessment, a plan to treat or manage your symptoms should be discussed and agreed with you.

The plan may include one or more of the following:

- modifying existing medication;
- ensuring your diet includes plenty of fruit, vegetables and wholegrain cereals;

- drinking appropriate amounts and types of fluid. It is important to drink enough fluid - around six glasses or one to one and a half litres per day. Restricting fluid can make matters worse. However you may be advised to limit fluid intake in the evening or avoid drinks which can irritate the bladder. These include tea, coffee, fizzy drinks and alcohol;
- taking regular light exercise;
- improving access to toilet facilities, providing aids such as raised toilet seats;
- choosing more easily removable clothing;
- explaining how to do pelvic floor exercises;
- introducing a bladder or bowel training programme;
- provision of pads, continence aids and other supplies.

If this is not successful, you may be referred to a hospital consultant for further investigation.

If you are eligible to receive long-term continence supplies you should be re-assessed at least annually. This will allow your needs to be reviewed and enable any new, possibly more suitable, products to be considered. If you feel your needs have changed, you can ask for a re-assessment.

If you believe it would be helpful to have a commode or learn about continence aids not available through the NHS, discuss this when you have your assessment. You could also contact one of the specialist organisations mentioned in Section 7. In some parts of the country, social services or the NHS offer a laundry service. You can ask about this when you have your assessment.

4. Buying or borrowing equipment and supplies

There may be times when you need additional equipment or clothing, particularly if you want to travel or be out for long periods of time. A wide range of products is available for sale. You can obtain information about suitable products and where to purchase them from your continence service, by asking your pharmacist or by contacting one of the organisations mentioned in Section 7.

If you live in your own home, you are entitled to buy many incontinence products without paying Value Added Tax (VAT). This rule also applies to supplies you buy over the internet or by mail order (as long as they are supplied to you as an individual). There is an exception to this VAT rule - VAT is charged on bed and furniture protection items.

Customs and Excise has automatically zero-rated certain continence products (for example, continence pads) in order to improve accessibility. For some products you will need to complete a VAT exemption certificate in order to receive products at their retail price less VAT. You should be advised of any VAT rules when making a purchase. The VAT relief does not apply to any postage or packaging charges incurred.

You may wish to borrow equipment such as a commode or raised toilet seat, especially if you are going to be away from home. Your local British Red Cross, local Age Concern, district nursing service or social services department may operate a loan service. See Age Concern Factsheet 42, *Disability equipment and how to get it*.

Disabled Living Centres

You can find advice and information on special clothing and equipment by contacting PromoCon or your local centre for independent living. Contact Assist UK or look on their website to see if there is a centre near you (see Section 7). You can make an appointment to discuss your needs, to see samples of some of the equipment and adapted clothing available and identify local or national suppliers.

5. Help in care homes

If you are about to move into a care home and have continence needs, these should be assessed by a trained health professional as part of your overall care assessment. Where possible you should be asked to take an active part in the assessment and discussion to agree how your continence needs might be met. Your continence needs should be included in your care plan. The effectiveness of the agreed treatment or management programme should be monitored and responded to.

If the assessment indicates that you need specialist continence supplies, you should not be asked to pay for them. This applies whether you are to be a self funding resident or to be supported by social services.

If your continence needs change, you should ask for them to be re-assessed.

If continence problems develop once you have moved into a care home, a specialist assessment may be needed. Your care plan will need to be revised to take account of newly identified continence needs. You should not be charged for any continence pads or other products you are assessed as needing.

It is important to ensure everything possible is being done to promote and help people manage their continence and maintain their independence and dignity.

If you have a relative about to move into or who is currently in a care home, ask whether people are helped to go to the toilet at regular intervals rather than just at mealtimes. Ask about toilet facilities and check accessibility, spaciousness and the presence of aids such as grab rails.

6. If you need to complain

Speak to your GP or the health professional who has been advising you, if you feel you are not receiving the advice or services you need. You may also like to discuss your concerns with a specialist nurse at the Continence Foundation (see Section 7).

If you remain dissatisfied, your local PALS will be able to give you information about the NHS complaints procedure. They can also help you find support to make a formal complaint if you need it. To identify the PALS that represents your PCT area, contact NHS Direct 0845 46 47 (lo-call rate).

7. Further information - organisations to contact

Assist UK, Redbank House, 4 St Chad's Street, Manchester M8 8QA, tel: 0870 770 2866 (national call rate), textphone: 0870 770 5813 (national call rate), website: www.assist-uk.org. *This national organisation was previously known as the Disabled Living Centres Council.* They can tell you if there is a centre near you offering free and ethical advice about continence aids and products.

British Red Cross, 44 Moorfields, London EC2Y 9AL, tel: 0870 170 7000 (national call rate), website: www.redcross.org.uk. Services mainly provided by volunteers and available from local centres including transport and escort, medical loan, emergency response, fire victims support, domiciliary care, Home from Hospital schemes and first aid. Copies of the catalogue of aids to buy, The Ability Mail Order, available by telephoning 0870 739 7391 (national call rate).

Continence Foundation (The), 307 Hatton Square, 16 Baldwins Gardens, London EC1N 7RJ, tel: 020 7404 6875, helpline: 0845 345 0165, 9.30am to 1.00pm Monday to Friday; website: www.continence-foundation.org.uk. The helpline is staffed by specialist nurses. They can provide general information on continence issues, an on-line directory of continence products and contact details for your local continence service.

If you prefer, you can write to the Helpline nurse or email your request to: continence-help@dial.pipex.com. If you email, remember to state your address so that any helpful publications can be sent to you. Any information will be sent in a plain envelope. Some publications can be downloaded from their website.

Disabled Living Foundation Helpline, 0845 130 9177 (lo-call rate) or textphone: 020 7432 8009, website: www.dlf.org.uk. Can discuss equipment for daily living; send written information on choosing the right product and details of product suppliers. This can also be downloaded via the website.

InContact, SATRA Innovation Park, Rockingham Road, Kettering, Northants NN16 9JH, tel: 01536 533255, website: www.incontact.org. A national charity for people affected by bowel and bladder problems. It is run by consumers and has a management team made up of consumers, informal carers and health professionals.

They produce a quarterly magazine and as well as a message board on their website, offer a support network in certain parts of the country. A range of booklets and information sheets are available to be downloaded from their website. Single copies can be sent free of charge to UK postal addresses only.

PromoCon, Redbank House, 4 St Chad's Street, Cheetham, Manchester M8 8QA, helpline 0161 834 2001, website: www.promocon.co.uk. They aim to help improve the life of adults and children with bowel and bladder problems by offering unbiased and detailed information on products, services and equipment (such as adaptive clothing, commodes, bed and furniture protection, continence pads and other personal items) specially designed for people with bladder and bowel difficulties.

The *National Display of Continence Products* is based at the Disabled Living Centre in Manchester. This Centre is open on weekdays only and it is essential to make an appointment to visit by calling 08707 601 580 (national call rate). There are over 3000 products on display.

RADAR, 12 City Forum, 250 City Road, London EC1V 8AF, tel: 020 7250 3222, minicom: 020 7250 4119, website: www.radar.org.uk. They organise the National Key Scheme for those disabled toilet facilities that have to be kept locked to prevent misuse and publish a guide to these facilities. Their publication "A Guide for disabled people - holidays in Britain and Ireland" includes holiday accommodation that caters for people with continence problems. There is a charge for both publications.

Further reading

The following publications are available from the Continence Foundation (individual copies are free of charge, but please send a large SAE) or bookshops. You may be able to borrow them from your local library.

Urinary incontinence in women. BMA Family Doctor Series. Price £4.25. This book explains the main types of incontinence and their treatments.

Women's waterworks: curing incontinence by Pauline Chiarelli 4th edition 2001 published by Neen Healthcare, tel: 0161 925 3180. This book is written by a physiotherapist and continence adviser and gives positive and encouraging advice about stress incontinence. £7.00 (inc postage & packing).

If ordering by post, please send a cheque or money order, payable to Age Concern England, for the appropriate amount plus p&p to Age Concern Books, Units 5 & 6, Industrial Estate, Brecon, Powys LD3 8LA.

(Postage and packing: mainland UK and Northern Ireland: £1.99 for the first book, 75p for each additional book up to a maximum of £7.50. Free on orders over £250. For customers ordering from outside the mainland UK & NI: credit card payments only; please telephone the hotline for international postage rates or **email:** sales@ageconcernbooks.co.uk):

If you would like

- to find your nearest Age Concern
- any additional factsheets mentioned (up to a maximum of 5 will be sent free of charge)
- a full list of factsheets and/or a book catalogue
- to receive this information in large print

phone 0800 00 99 66 (free call) or write to Age Concern FREEPOST (SWB 30375), Ashburton, Devon TQ13 7ZZ. For people with hearing loss who have access to a textphone, calls can be made by Typetalk, which relays conversations between text and voice via an operator.

Age Concern factsheets and other information materials can be downloaded free from our website at: www.ageconcern.org.uk. To receive a free e-mail notification when new and updated factsheets are published, please contact the Factsheet Subscription Service on 020 8765 7200.

Age Concern provides factsheets free to older people, their families and people who work with them.

If you would like to make a donation to our work, you can send a cheque or postal order (made payable to Age Concern England) to the Personal Fundraising Department, ACE Freepost CN1794, London SW16 4BR.

Find out more about Age Concern England online at: www.ageconcern.org.uk

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No factsheet can ever be a complete guide to the law, which also changes from time to time. Therefore please ensure that you have an up to date factsheet and that it clearly applies to your situation. Legal advice should always be taken if you are in doubt. (*Age Concern England is unable to give financial or legal advice*).

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