



Royal College
of Physicians

Keeping control

What you should expect
from your NHS bladder
and bowel service

Based on findings from the national
audit of continence care 2010

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Healthcare Quality
Improvement Partnership

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Royal College of Physicians

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Explanation of words used in this booklet

Word/term	Explanation
Assessment	This involves understanding what the causes of the problem are, and what the needs of the patient are, by talking with the patient and doing a physical examination and sometimes tests.
Bladder incontinence	Bladder or urinary incontinence is any inability to control the passing of urine.
Bowel incontinence	Bowel or faecal incontinence is any loss of control of the bowels.
Care home	This covers residential and nursing homes.
Community	This covers GP surgeries and community continence clinics.
Continence advisers	Experienced nurses who have undertaken specialist training to help people with this type of problem.
Continence pad	Product used to protect both undergarments and the skin in people with incontinence.
Continence service	Bladder and bowel service.
Continence specialists	These can be nurses, physiotherapists or specialist hospital doctors (eg urologists, gynaecologists, gastroenterologists, geriatricians).
Diagnosis	This involves finding out the causes of the medical problem by doing an assessment, and then explaining it, and what treatments are available to the patient.

Word/term	Explanation
Healthcare provider	This can be a hospital, GP, nursing home, care home, community clinic, or primary care centre.
Healthcare staff	These can be hospital ward nurses, care home workers or GPs.
Hospital	This includes hospital wards and outpatient clinics.
Mental health service	This provides community, health and social care services for people with mental health problems.
National audit	This is a way to measure the performance and the quality of care across the UK and bring about improvements using the information collected.
Prolapse examination	The doctor or nurse will check for any weakness of the muscles around the bladder and rectum (back passage).
Prostate gland	This is a gland in men located below the bladder. As men get older, this enlarges and may cause obstruction to the normal flow of urine.
Symptoms	Continence symptoms include the urgent need to go to the toilet, leaking urine when you cough, getting up several times at night to pass urine, or feeling constipated.

Introduction

Many people with bladder and bowel incontinence suffer in silence, too embarrassed to seek help. The NHS needs to make sure that people with incontinence problems are able to talk to their healthcare staff.

‘Even though about six million people in the UK suffer from bladder and bowel incontinence, continence advisers are not considered essential within the NHS...’

Hospital doctor

► In September 2010, the Royal College of Physicians published audit findings about the services and quality of care of people with bladder and bowel incontinence in England, Wales and Northern Ireland. The audit was commissioned by the Healthcare Quality and Improvement Partnership. This report described in detail the care given to 18,253 people with continence problems in a variety of NHS settings such as hospital wards, hospital outpatient clinics, mental health hospitals, GP surgeries, and care homes. Staff working in these settings took part by submitting information for the audit. The audit asked key questions about how continence care was being delivered to patients.

The results were sent back to every organisation that took part with a request that staff look at areas where continence care was below standard, and to develop plans to improve services. The results were also made available to the public so that people could see how their local healthcare provider had performed. However, the report was 161 pages long, with much technical information, and was mainly written for health service managers and staff working in continence services.

Overall, this audit showed that there is a real need for an improvement in continence care for people with bladder and bowel problems. One way to do this is to provide information directly to people using these services. So, we met and talked to people who have used continence services, and with other groups such as Age UK and the Bladder and Bowel Foundation, to ask what audit information they wanted to see in a more user-friendly report and how it should be presented, and this is the result.

This booklet contains key messages from the audit and information about what care people can expect if they seek help for bladder or bowel problems.

What to expect from a good continence service

A good continence service should be led by continence specialists, with services (eg assessment, investigation) linked to each other so that people progress easily through the service, from assessment to successful treatment, and do not get ‘stuck’ or ‘forgotten’ at any stage.

‘... In the past year a number of continence adviser jobs in the NHS have been cut and the standards of continence care have suffered.’

Hospital doctor

➤ **If you go to see healthcare staff about your bladder or bowel problem, you should expect to:**

- > be seen and examined by a nurse or doctor who is trained to do an assessment
- > see a specialist who is able to answer your questions relating to your incontinence, can provide a diagnosis and discuss all available treatments
- > always be treated with sensitivity. This can be a distressing time and you should be made to feel as comfortable as possible at all times
- > have different treatment options available to you regardless of your age
- > have information available not only about your NHS service but also about what you can do to help yourself
- > be provided with details of user groups that you can join. Patient groups can provide ways of finding out about service changes and how you can affect them.

If this does not happen, what should you do?

- > If your area does not have a user or patient group, push to get one set up. You can do this by contacting the primary care organisation, community continence advisers, GPs and general practice staff, to ask them for advice on setting one up.
- > Ask at your local hospital or GP surgery for the contact details of your local Patient Advice and Liaison Service (PALS) service (see end of booklet). You can use the PALS service to get further advice or make a complaint.
- > You can also contact organisations like the Bladder and Bowel Foundation (BBF) if you require further help and assistance.

What to expect from good standards of assessment

When you have bladder or bowel incontinence, you need to be properly assessed in order to be given a diagnosis and a treatment plan.

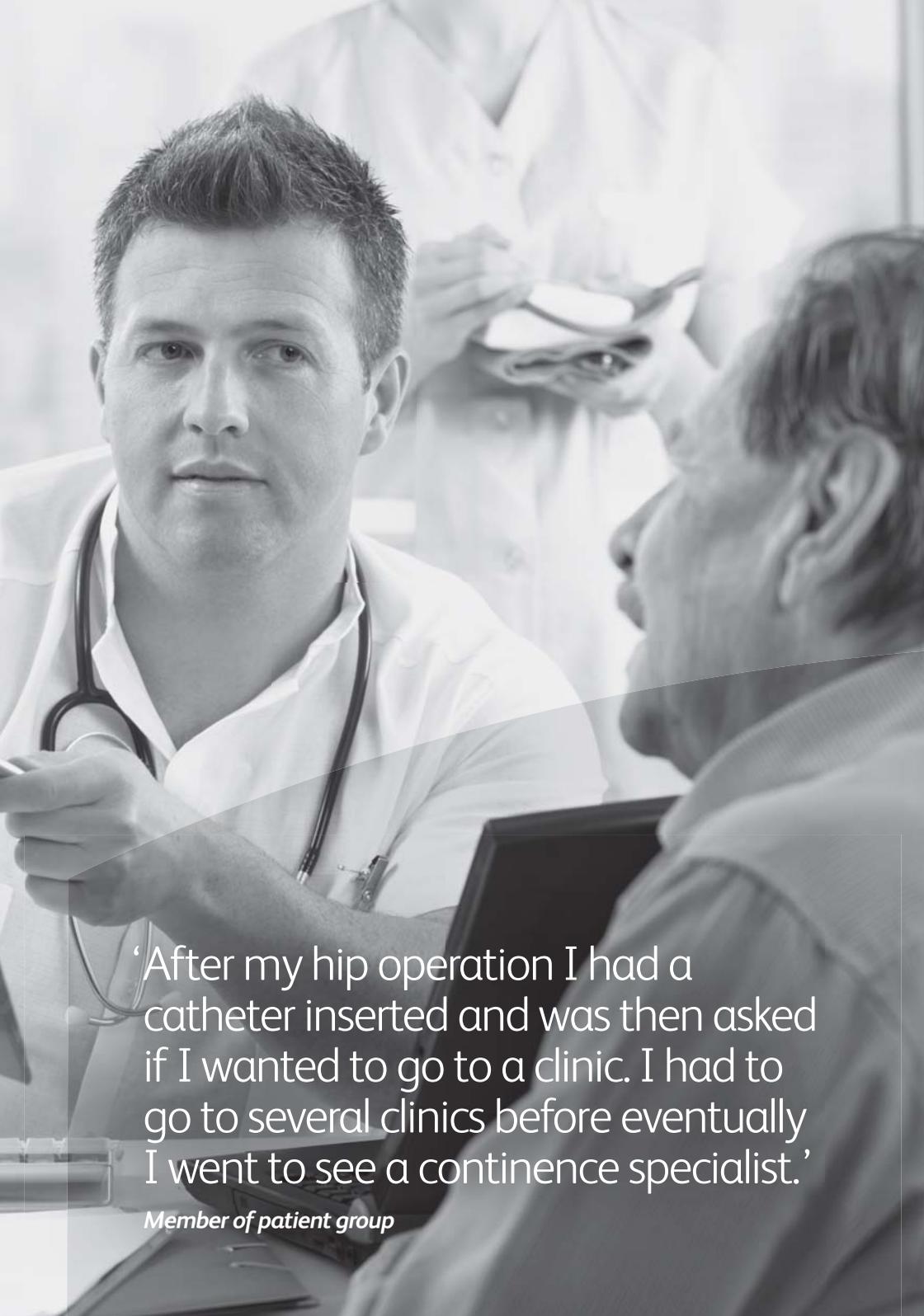
- **If you go to see healthcare staff about your bladder or bowel problem, you should expect to:**
 - > be asked about your symptoms to find out what type of bladder or bowel problem you have
 - > be asked whether you have any medical conditions that could be part of the cause
 - > be asked about the medication you are taking as it could be causing your problem or making it worse
 - > have tests to see if there is an infection, and complete daily/weekly charts to record how often you go to the toilet. These are a great help in deciding on the correct treatment
 - > have an ‘internal’ examination (with your consent) – in women to check for prolapse and in men to assess the prostate gland

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‘There was only one incontinence district nurse for my area. This makes her very busy. I found some staff that are reliable and some that are not. They should all be trained.’

Member of patient group



‘After my hip operation I had a catheter inserted and was then asked if I wanted to go to a clinic. I had to go to several clinics before eventually I went to see a continence specialist.’

Member of patient group

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- > be asked how much your bladder or bowel problem affects your life, how you deal with the problem and what you would like the result of treatment to be
- > be given advice to follow to see if this may help, such as cutting out all drinks containing caffeine, or increasing the amount you drink in the case of constipation. Be given products such as pads and also advice on how to protect your skin
- > discuss whether there is a need to refer you (send you on) to someone else for further help
- > talk about treatment choices and give you a clear 'treatment plan'. A treatment plan will explain what you can do to help, and what the healthcare staff will do/provide. It will also tell you when you will be seen again and what the next steps are.

If this does not happen, what should you do?

- > Contact your GP surgery or practice nurse and take this booklet with you. Tell them that you want to be seen by a continence specialist, and that you would like to receive a thorough examination from the specialist.
- > Ask at your local hospital or GP surgery for the contact details of your local Patient Advice and Liaison Service (PALS) service (see end of booklet). You can use the PALS service to get further advice or make a complaint.

What to expect from good standards of diagnosis and treatment

If your assessment is not done well, this can result in you not getting a proper diagnosis or the treatment you need for your continence problem.

➤ **If you go to see healthcare staff about your bladder or bowel problem, you should expect to:**

- > have a detailed assessment performed, be told the results and the possible cause of your incontinence
- > discuss what treatments are available
- > discuss plans for future treatment with you so that what you want is taken into account. You should always be involved in making a treatment plan; you should be given a copy of the plan, have this explained to you, and be involved in regular reviews of your plan to make sure it is working.

If this does not happen, what should you do?

- > Ask questions of your doctor or nurse.
- > Ask to see your treatment plan in writing, if you have not received one already.
- > Ask to have your treatment explained to you at all times.



‘I was given plenty of information and paperwork, I found this invaluable as it helped me follow my progress. I think, though, that the treatment plan should be updated more often.’

Member of patient group

Audit background

Standards for a good continence service

A good continence service will make sure that healthcare staff are trained in continence care and that patients receive good information throughout their treatment. A continence service that ticks all these boxes is what is called an ‘integrated’ service, so we asked questions relating to an integrated service.

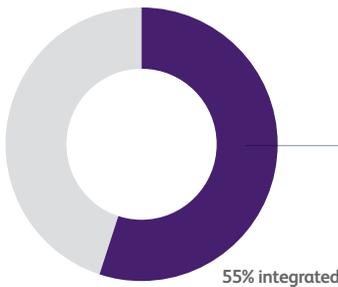


Fig 1 Integrated continence services in hospitals (%)

1 Do you have an integrated continence service?

The audit found that only 55% of continence services in hospital in our sample were integrated (see fig 1), which means a lack of joined-up care. For example: A person may tell the hospital ward staff that they have incontinence – they may be given pads to take home but no further information is provided, and plans for assessment and treatment of their incontinence are not made.

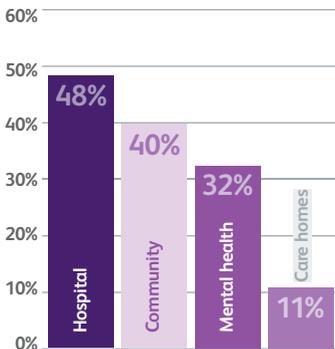


Fig 2 Services with lead person (%)

2 Does your service have a director or lead?

Less than half of services had a lead person (see fig 2). This means that no one is directly responsible for organising and improving continence services. Hospitals, GP surgeries and community services should make sure that services are integrated, and that they have a named person who is responsible for continence services.

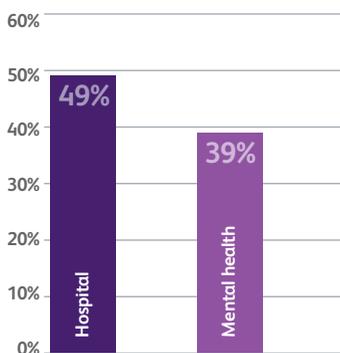


Fig 3 Services with training provided (%)

3 Is training in continence care provided?

Healthcare staff who provide day-to-day care to patients (such as GPs, ward nurses and doctors and care home staff) should be trained in how to assess and manage incontinence. In our audit we asked about the continence training given to healthcare staff. We found that training relating to continence care was provided in less than 50% of hospitals and in only 40% of mental health services (see fig 3).

It is important that healthcare staff have the proper training so that they know how to help you with your incontinence concerns. This training is often carried out by continence advisers who are experienced, qualified nurses with specialist training in helping people with this type of problem. Our audit showed that hospitals with a high number of continence advisers provided higher standards of care in their continence service.

Assessment

In the audit we asked about good standards of assessment.

Incontinence can have a devastating effect on life and an important part of assessment is for you to be asked about how it is affecting your daily life. This is called a quality of life assessment. In hospitals, we found that quality of life was only assessed in a third of older people and in just under half of younger people with urinary incontinence.

A physical examination is a necessary part of assessment, but we found that almost one third of older patients in hospital did not receive this examination.

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Overall, we found that some people are getting very good assessments, while others are not getting the continence assessment that they should. This often depends on whether there is a continence service or continence advisers in the local area – and whether that service (if it exists) is integrated.

Diagnosis and treatment

The audit found that discovering the cause (making a diagnosis) of why people are incontinent is often not done. The audit also showed that many people are not receiving information about the causes and possible treatments for their incontinence.

Did everyone no matter what age get the same service?

The audit found that some patients were not given a clear diagnosis or treatment plans, and were not informed about the causes and treatment choices for their urinary incontinence (see fig 4).

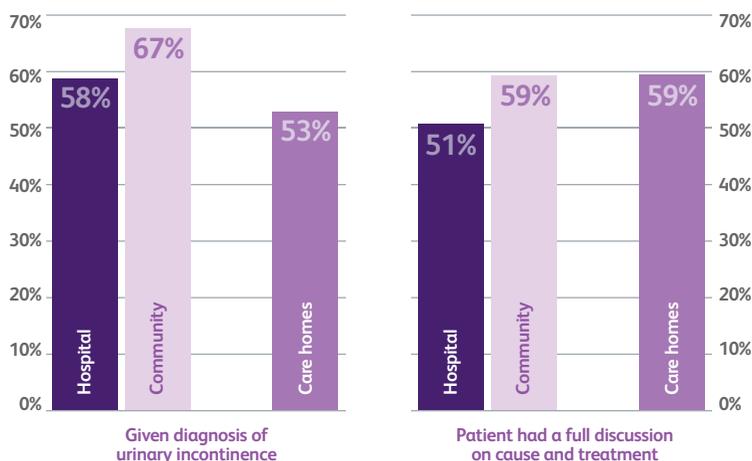


Fig 4 Patients receiving clear diagnosis and information (%)

Where to go for more information

Bladder and Bowel Foundation www.bladderandbowelfoundation.org

Provides information, help and support for adults, who have experienced either a bladder or bowel problem.

Helpline: +44 (0)845 345 0165 Email: info@bladderandbowelfoundation.org

Age UK www.ageuk.org.uk

Provides advice and information for older people.

Tel: +44 (0)800 169 8787 Email: contact@ageuk.org.uk

Patient Advice and Liaison Service (PALS) www.pals.nhs.uk

Ask at your local hospital or GP for information about your local PALS service or go on to the website to find your local PALS service. You can then call or visit your local service and ask for advice and help with any health-related enquiry.

Notes and information

Name of local continence adviser:

Contact details:

Notes:

People suffering with incontinence can often be too embarrassed to come forward and seek help for it. It is not an easy subject to discuss with your doctor or nurse. So it is important that you are asked if you have any problems getting to the toilet on time. There is something that can be done and you can get help – it is not something you have to put up with. There should be help available whether you visit a GP, a nurse or you are in hospital.

To see or download the full National Audit of Continence Care report, please go to:
www.rcplondon.ac.uk/resources/national-audit-continence-care

We would like your feedback

For more copies of this booklet or to feed back about how useful it is, please contact:
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