

Understanding NICE guidance

Information for people who use NHS services

Faecal incontinence (bowel control problems)

NICE 'clinical guidelines' advise the NHS on caring for people with specific conditions or diseases and the treatments they should receive.

This booklet is about the care and treatment of people with faecal incontinence (bowel control problems) in the NHS in England and Wales. It explains guidance (advice) from NICE (the National Institute for Health and Clinical Excellence). It is written for people with faecal incontinence but it may also be useful for their families or carers or for anyone with an interest in the condition.

The booklet aims to help you understand the care and treatment options that should be available in the NHS. It does not describe faecal incontinence or the tests or treatments for it in detail. A member of your healthcare team should discuss these with you. There are examples of questions you could ask throughout this booklet to help you with this. Some sources of further information and support are on page 15. Medical terms printed in bold type are explained on page 14.

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The advice in the NICE guideline covers the care of adults with faecal incontinence. It does not specifically look at:

- faecal incontinence in people under the age of 18 years
- urinary incontinence (the leakage of urine when you do not mean to urinate [pass water]).

Your care

Your treatment and care should take into account your personal needs and preferences, and you have the right to be fully informed and to make decisions in partnership with your healthcare team. To help with this, your healthcare team should give you information you can understand and that is relevant to your circumstances. All healthcare professionals should treat you with respect, sensitivity and understanding and explain faecal incontinence and the treatments for it simply and clearly. The people who work with you to manage your faecal incontinence should have the relevant skills, training and experience. They should work together closely to ensure you get sensitive and supportive care.

The information you get from your healthcare team should include details of the possible benefits and risks of particular treatments. You can ask any questions you want to and can always change your mind as your treatment progresses or your condition or circumstances change. Your own preference for a particular treatment is important and your healthcare team should support your choice of treatment wherever possible.

Your treatment and care, and the information you are given about it, should take account of any religious, ethnic or cultural needs you may have. It should also take into account any additional factors, such as physical or learning disabilities, sight or hearing problems, or difficulties with reading or speaking English. Your healthcare team should be able to arrange an interpreter or an advocate (someone who supports you in putting across your views) if needed.

If you agree, your carers and relatives should have the chance to be involved in decisions about your care. Carers and relatives also have the right to the information and support they need in their roles as carers.

If people are unable to understand a particular issue or are not able to make decisions for themselves, healthcare professionals should follow the advice that the Department of Health has produced about this. You can find this by going to the Department of Health website (www.dh.gov.uk/consent). Your healthcare professional should also follow the new Mental Capacity Act. For more information about this, visit www.direct.gov.uk and search for 'capacity'.

Some treatments may not be suitable for you, depending on your exact circumstances. If you have questions about the specific treatments and options covered in this booklet, please talk to a member of your healthcare team.

If you think that your care does not match what is described in this booklet, please talk to a member of your healthcare team.

What is faecal incontinence?

Faecal incontinence occurs when people lose the ability to control their bowel movements, resulting in unplanned leakage of **faeces**. It is estimated that faecal incontinence affects up to 1 in 10 people at some time in their lives. They may have bowel accidents that are caused by not being able to get to a toilet quickly enough, or they may experience soiling or leaking from the bowel without being aware of it.

Faecal incontinence may have many different causes. It can be distressing and can severely affect everyday life. Many people with faecal incontinence find it very difficult and embarrassing to talk about it to doctors and nurses, or to tell their family and friends. Once faecal incontinence has been identified there are treatments that can help manage or sometimes cure it, as well as strategies to help people cope with the condition and discuss it openly.

Questions you might like to ask your healthcare team

- Are there any organisations that could give me more information about faecal incontinence?
- Are there any support organisations?
- Can you provide any information for my family/carers?
- Can you suggest ways I can tell my family and friends about my problem?

Finding out what is wrong

People at risk

There are certain groups of people who are more likely to have faecal incontinence than others. Healthcare professionals should ask people (or their carers) whether they experience faecal incontinence if they are in one of the following groups:

- frail older people
- people with loose stools or diarrhoea
- women who have recently given birth
- people who have injury to or disease of their nervous system or spinal cord
- people with learning disabilities or memory problems
- people with urinary incontinence
- people who have had a prolapse of their **rectum** or organs in their **pelvis** (this means that these organs have slipped down from their usual position in the body)
- people who have had an operation on their **colon** (part of the bowel) or **anus**
- people who have had radiotherapy to their pelvic area
- people with soreness or itching around the anus.

Preventing problems with incontinence

Healthcare professionals should consider offering help with bowel management to the following groups of people, to prevent problems with incontinence:

- people who have a disease or injury of their brain, nerves or spine
- people with limited mobility (who cannot get to the toilet easily)
- people with constipation or **faecal loading** (there is more information about this on page 11)
- people in hospital who develop short-term faecal loading and incontinence
- people with learning disabilities or memory problems.

Assessing faecal incontinence

Faecal incontinence can have many different causes. Your healthcare professional should first carry out a full assessment of your condition to ensure you get the most appropriate treatment. This is known as a 'baseline assessment' and should include asking about your medical history. Some questions you may be asked are given below.

Examples of questions you may be asked

- When/how often do you usually empty your bowel? Has this changed recently?
- Have you had any bleeding?
- Do you need help using or getting to the toilet?
- What medicines are you taking, including those bought from a chemist?
- How much fluid do you drink each day?
- What types of food do you eat?
- Do you experience itching or soreness around your anus?
- How do your symptoms affect your daily life?

Your healthcare professional should ask permission to examine your anus and rectum.

Dealing with faecal incontinence

As part of your assessment, you should be given advice to help you deal with your incontinence. Your healthcare professional should tell you about continence products available and how to use them, including disposable pads. You should be offered a choice of pad styles and given enough pads for your needs. You may also be offered anal plugs (to insert in the anus to prevent leakage of faeces) if they are suitable for you.

Your healthcare professional should give you advice about how to clean and protect your skin, to stop it getting sore. You should be offered advice on odour control and how to deal with your laundry.

Your healthcare professional should give you information about emotional support, and counselling if you need it.

If you need to travel, you should be given advice on how to plan journeys so that you can use public toilets. You should also be told about a toilet access card and a RADAR key. The toilet access card is a small card you can carry that explains that you have a medical condition that means you need to use the toilet urgently. The RADAR key allows you to use 'disabled' toilets in the National Key Scheme. For more information see www.radar.org.uk/radarwebsite/tabid/41/default.aspx

Treating conditions that can cause faecal incontinence

Some conditions that can cause faecal incontinence should be treated first, before your doctor offers any treatment for the incontinence itself. These conditions are:

- faecal loading
- diarrhoea (including inflammatory bowel disease and irritable bowel syndrome, and diarrhoea caused by infection)
- signs of cancer of the **bowel**, rectum or anus
- prolapse of the rectum
- third-degree haemorrhoids (severe piles that extend from the anus)
- recent injury to the **anal sphincter**
- a 'slipped disc' in your back.

First steps: managing faecal incontinence

Your healthcare professional should explain that you may need to try several different strategies to help manage your incontinence.

Your bowel habit

Management of your faecal incontinence can be helped by ensuring that you have bowel movements at specific times during the day. Your healthcare professional should:

- encourage you to use the toilet after a meal
- make sure you have access to private, comfortable and safe toilet facilities that you can use for as long as you need
- encourage you to sit or squat where possible when emptying your bowel
- teach you how to empty your bowel without straining.

Your diet

You should be given advice about changing your diet, because the type of food you eat and the amount of fluid you drink can help with regular bowel movements and the firmness of your stools. You may be asked to keep a diary of your food and fluid intake so that any changes can take into account your current diet. Any changes should also consider particular dietary needs that you may have. You may be checked for signs of malnutrition.

Questions about diet

- Are there foods that could be making my incontinence worse?
- Are there foods I could try that would help avoid constipation?
- How much fluid should I drink?

Access to the toilet

A very important way of helping you manage your incontinence is to make sure you can use the toilet as easily as possible. A healthcare professional may assess your home and your mobility to see what extra help you might need. You should be given advice about clothing that is easy to remove so that you can use the toilet more quickly.

Any equipment needed to help you get to the toilet should be provided. If you are in a hospital or care home, toilets should be easy to find.

Help to use the toilet should always be available if you need it. Your privacy and dignity should always be respected.

Your existing medicines

If you are taking any medicines your healthcare professional should consider whether this is making your incontinence worse, and if so offer a different treatment if possible.

Medicines for faecal incontinence

If you have faecal incontinence with loose stools, you should usually be offered a drug that stops diarrhoea, as long as the problem isn't caused by your diet or by laxatives. In most cases (see below) the first drug you should be offered is loperamide, which you can take for as long as you need. You can change the dose, and stop and start taking loperamide as needed, depending on the consistency of your stools and on your lifestyle. If you are taking a low dose of loperamide, you may be offered loperamide syrup instead of tablets. However, you should not be offered loperamide if you have hard or infrequent stools, acute diarrhoea without a diagnosed cause, or an acute flare-up of **ulcerative colitis**.

Questions about medicines

- How long will I have to take the medicine for?
- What benefits should I expect?
- Is it important to take the medicine regularly, or can I take it as and when I need it?
- Are there any serious side effects associated with this medicine?

Review and long-term management

After each stage of your treatment, your healthcare professional should ask whether it has helped you. If it hasn't helped, you should be able to discuss other options.

If you decide not to have any more treatment for your incontinence, or if it doesn't improve, you should be given practical and emotional help as described in this booklet. You should also be offered 6-monthly check-ups and given advice about how to maintain your dignity and independence. Your healthcare professional may suggest that you see a therapist or counsellor if this might help you to cope with your condition better. You should receive continuing advice about other treatment options, including referral to a specialist.

Next steps: specialised management

If the first steps in managing faecal incontinence don't help you, you may be referred to a specialist continence service. Here you will have the chance to discuss whether any of the following options may be suitable for you:

- **pelvic floor** muscle exercises (to improve the coordination and strength of the pelvic muscles)
- bowel retraining (education about how the bowel works, and training to modify bowel function)
- specialist dietary assessment and management
- biofeedback (this includes aspects of bowel retraining and also physical treatments to improve bowel and pelvic floor coordination)
- electrical stimulation (applying tiny, safe electric currents to the anus in order to improve coordination and strength)
- **rectal irrigation.**

If you opt for pelvic floor muscle exercises, a trained healthcare professional should plan a programme with you, including regular assessment of your symptoms to see how well the exercises are going.

What happens if specialised management does not work?

If the treatments mentioned above haven't helped you, your healthcare professional should consider referring you for special tests.

Advice for specific groups of people

The way in which faecal incontinence is assessed and managed will also depend on whether any of the following apply to you or the person you care for.

- If you have faecal loading you will be offered medicines to encourage the bowel to empty. First you should be offered medicines that are put in the rectum. If these do not work, you may also be given a strong laxative to swallow, and the side effects associated with this medicine should be explained to you.
- You may be offered medicine to help you empty your bowel. If you have a carer you should take your medicine at a pre-planned time so that your carer is there to help you when you need the toilet.
- If you (or the person you care for) have severe problems with memory or learning disabilities, you should be assessed to see whether there is any behavioural reason for your faecal incontinence. If so, appropriate treatment should be started.
- If you have a neurological condition (a condition of the nervous system) or spinal problems you should be offered specific treatment that is based on your own preferences and takes into account how your bowel has been affected by disease or injury. You should also be given general advice on coping and long-term management (see page 10). You may be offered further treatments if managing your incontinence severely limits your lifestyle. These treatments may include rectal irrigation, or surgery (see page 12).
- If you are being fed through a tube and have problems with incontinence, the type and timing of your feeds should be adjusted.

Questions for family members, friends and carers

- What can I/we do to help and support the person with faecal incontinence?
- Is there any additional support that I/we as carer(s) might benefit from or are entitled to?

It is essential that people with learning disabilities have the same care and treatment during assessment and management of faecal incontinence as other people do. People with learning disabilities – whether they have had faecal incontinence from childhood or have experienced it for the first time as an adult – may need additional support to cope as well as other people.

Questions about treatment

- Please tell me why you have decided to offer me this particular type of treatment.
- What are the pros and cons of having this treatment?
- Please tell me what the treatment will involve.
- How will the treatment help me? What effect will it have on my symptoms and everyday life? What sort of improvements might I expect?
- How long will it take to have an effect?
- Are there any risks associated with this treatment?
- Is there some written information (like a leaflet) about the treatment that I can have?

If you need surgery

If your doctor thinks surgery might help you, he or she should refer you to a specialist surgeon. The surgeon should discuss the possible options with you, explaining the risks and benefits and how likely the operation is to work.

The type of operation offered will depend on what is causing your incontinence. For example, if you have a defect in your anal sphincter you may be offered an operation to repair it. If this is not suitable for you, the following surgical procedures may be considered. If you decide to have one of them you should be offered ongoing support to help you.

- Stimulated graciloplasty involves making a new anal sphincter from muscle taken from the thigh. Electrical stimulation is applied to this new sphincter to strengthen it. For more information see www.nice.org.uk/IPG159publicinfo
- Artificial anal sphincter implantation involves placing a circular cuff under the skin around the anus, to allow you to control when you empty your bowel. For more information see www.nice.org.uk/IPG066publicinfo

- Sacral nerve stimulation is a way of using electrical pulses to keep the anal sphincter closed. It involves inserting electrodes under the skin in the lower back. For more information see www.nice.org.uk/IPG099publicinfo
- Antegrade irrigation involves washing out the colon with water, using a tube going through the wall of the **abdomen** into the appendix.

If there are no suitable treatments, your doctor may consider offering you a stoma if you have incontinence that severely affects your everyday life. A stoma is an opening from your bowel through your abdomen, created by a surgeon. If this is the case, you will first be seen by a specialist stoma care service and your doctor will explain all the risks, benefits and long-term effects to you.

Questions about surgery

- Is there an operation that might help my condition?
- What are the risks and benefits of the operation?
- Are the risks minor or serious? How likely are they to happen?
- How likely is it to work in the long term?
- Can the operation be reversed?
- Can you tell me about other surgical procedures that might help?
- Has NICE published any guidance on these procedures?
- What are the alternative treatment options?

If a treatment described in this booklet appears suitable for you, but it is not available, you should talk to your local Patient Advice and Liaison Service (PALS) in the first instance. If they are not able to help you, they should refer you to your local Independent Complaints Advocacy Service.

Glossary

Abdomen The lower part of the trunk of the body, below the chest and above the hips, that contains the stomach, **bowel** and other abdominal organs.

Anal sphincter The ring of muscle that controls the opening and closing of the **anus**.

Anus The opening to the outside of the body at the end of the digestive system. It is where solid waste leaves the body.

Bowel The lower part of the digestive system, below the stomach. The **colon** and **rectum** are parts of the bowel.

Colon The part of the **bowel** where **faeces** are formed and are passed on to the **rectum**.

Faecal loading The presence of a large amount of **faeces** in the **rectum**.

Faeces Also known as motion or stools, this is solid or semi-solid waste material that is passed out of the body through the anus.

Pelvis The lower part of the **abdomen** between the hips. The pelvis contains the reproductive organs, bladder and other pelvic organs.

Pelvic floor A group of muscles that lie across the base of the **abdomen**. They play an important role in controlling the passing of **faeces** or urine.

Rectal irrigation Washing out the **rectum** with warm water.

Rectum The lower part of the **bowel**, that ends with the **anus**.

Ulcerative colitis Inflammation of the colon and rectum.

More information

The organisations below can provide more information and support for people with faecal incontinence. Please note that NICE is not responsible for the quality or accuracy of any information or advice provided by these organisations.

- Continence Foundation, 0845 345 0165, www.continence-foundation.org.uk
- The IBS Network, 0114 272 3253, www.ibsnetwork.org.uk
- *Incontact*, 0870 770 3246, www.incontact.org
- National Association for Colitis and Crohn's Disease (NACC), 0845 130 2233, www.nacc.org.uk
- Spinal Injuries Association, 0800 980 0501, www.spinal.co.uk

NHS Direct online (www.nhsdirect.nhs.uk) may be a good starting point for finding out more. Your local Patient Advice and Liaison Service (PALS) may also be able to give you further information and support. There is also information on the NICE website about the surgical procedures mentioned in this document.

About NICE

NICE produces guidance (advice) for the NHS about preventing, diagnosing and treating different medical conditions. The guidance is written by independent experts including healthcare professionals and people representing patients and carers. They consider the best available evidence on the condition and treatments, the views of patients and carers and the experiences of doctors, nurses and other healthcare professionals working in the field. Staff working in the NHS are expected to follow this guidance.

To find out more about NICE, its work and how it reaches decisions, see www.nice.org.uk/aboutguidance

This booklet and other versions of this guideline aimed at healthcare professionals are available at www.nice.org.uk/CG049

You can order printed copies of this booklet from the NHS Response Line (phone 0870 1555 455 and quote reference N1264).