

# Faecal incontinence

The management of faecal incontinence in adults

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## Introduction

Faecal incontinence is a sign or a symptom, not a diagnosis. Therefore, it is important to diagnose the cause or causes for each individual. Because it is a stigmatising condition, active case-finding will often be needed, probably best targeted at high-risk groups.

Current epidemiological information shows that between 1% and 10% of adults are affected with faecal incontinence, depending on the definition and frequency of faecal incontinence used. It is likely that 0.5–1.0% of adults experience regular faecal incontinence that affects their quality of life. Little is known about the natural history of the condition but for some groups (such as women immediately after childbirth) there does seem to be some spontaneous resolution of symptoms. For understandable reasons, faecal incontinence has remained a largely hidden problem, with many patients feeling too embarrassed or ashamed to admit their symptoms to healthcare professionals, or even to family and friends.

There is no consensus on methods of classifying the symptoms and causes of faecal incontinence. It is most commonly classified according to symptom, character of the leakage, patient group or presumed primary underlying cause. For many people faecal incontinence is the result of a complex interplay of contributing factors, many of which can co-exist. Some factors may be relatively simple to reverse. Therefore, a detailed initial assessment and structured approach to management is needed, starting with addressing reversible factors and, only if this fails to restore continence, progressing to specialised options and investigations.

## Person-centred care

This guideline offers best practice advice on the care of adults with faecal incontinence.

All staff working with people with faecal incontinence should be aware of both the physical and the emotional impact this condition can have on people and their carers. Treatment and care should take account of individual needs and preferences. People with faecal incontinence should have the opportunity to make informed decisions about their care and treatment, in partnership with their healthcare professionals. It should be recognised that people who have had faecal incontinence for a long time may become experts in the management of their symptoms. Where it is believed that a person may lack the capacity to make decisions, healthcare professionals should follow the Department of Health's advice on consent and the code of practice that accompanies the Mental Capacity Act. In Wales, healthcare professionals should follow advice on consent from the Welsh Government.

Treatment and care and the information people are given about faecal incontinence should be culturally appropriate. Information should be accessible to people with additional needs such as physical, sensory, mental or learning disabilities. Specialist techniques and tools should be employed to ensure that people with communication difficulties have the opportunity to receive information. It should be offered in a wide range of languages and formats (including face-toface, telephone-based, web-based, electronic, printed and audiotape). Specific strategies are needed to meet the information and advice needs of groups who may be less likely to seek help or information. These could include people from groups where the condition is seen as particularly stigmatising. Advice on the production of public and patient information by healthcare professionals is available from www.nhsidentity.nhs.uk. Information by itself is not always enough: people should be offered one-to-one support in understanding and interpreting information and what it means for them as individuals. Carers and relatives should have the opportunity to be involved in decisions about the patient's care and treatment, if the patient agrees to this. Because of the sensitive nature of the condition and the stigma attached to it, people should be asked if they want carers and relatives to be involved. In some cultures disclosure of faecal incontinence could lead to the person being ostracised. Where appropriate, carers and relatives should also be given the information and support they need.

## **Key priorities for implementation**

### Good practice in managing faecal incontinence

- People who report or are reported to have faecal incontinence should be offered care to be managed by healthcare professionals who have the relevant skills, training and experience and who work within an integrated continence service<sup>[1]</sup>.
- Because faecal incontinence is a socially stigmatising condition, healthcare professionals should actively yet sensitively enquire about symptoms in high-risk groups (see box 1):

### **Box 1 High-risk groups**

- frail older people
- people with loose stools or diarrhoea from any cause
- women following childbirth (especially following third- and fourth- degree obstetric injury)
- people with neurological or spinal disease/injury (for example, spina bifida, stroke, multiple sclerosis, spinal cord injury)
- people with severe cognitive impairment
- people with urinary incontinence
- people with pelvic organ prolapse and/or rectal prolapse
- people who have had colonic resection or anal surgery
- people who have undergone pelvic radiotherapy
- people with perianal soreness, itching or pain
- people with learning disabilities
- When assessing faecal incontinence healthcare professionals should:
  - be aware that faecal incontinence is a symptom, often with multiple contributory factors for an individual patient

 avoid making simplistic assumptions that causation is related to a single primary diagnosis ('diagnostic overshadowing').

### Baseline assessment and initial management

- Healthcare professionals should carry out and record a focused baseline assessment for people with faecal incontinence to identify the contributory factors. This should comprise:
  - relevant medical history
  - a general examination
  - an anorectal examination
  - a cognitive assessment, if appropriate.
- People with the following conditions should have these addressed with condition-specific interventions before healthcare professionals progress to initial management of faecal incontinence:
  - faecal loading (see also section 1.7.3)
  - potentially treatable causes of diarrhoea (for example infective, inflammatory bowel disease and irritable bowel syndrome)
  - warning signs for lower gastrointestinal cancer[2]
  - rectal prolapse or third-degree haemorrhoids
  - acute anal sphincter injury including obstetric and other trauma
  - acute disc prolapse/cauda equina syndrome.
- Healthcare professionals should address the individual's bowel habit, aiming for ideal stool consistency and satisfactory bowel emptying at a predictable time.

#### Specialised management

• People who continue to have episodes of faecal incontinence after initial management should be considered for specialised management. This may involve referral to a specialist continence service, which may include:

- pelvic floor muscle training
- bowel retraining
- specialist dietary assessment and management
- biofeedback
- electrical stimulation
- rectal irrigation.

Some of these treatments might not be appropriate for people who are unable to understand and/or comply with instructions<sup>[3]</sup>.

### Long-term management

- Healthcare professionals should offer the following to symptomatic people who do not wish to continue with active treatment or who have intractable faecal incontinence:
  - advice relating to the preservation of dignity and, where possible, independence
  - psychological and emotional support, possibly including referral to counsellors or therapists if it seems likely that people's attitude towards their condition and their ability to manage and cope with faecal incontinence could improve with professional assistance
  - at least 6-monthly review of symptoms
  - discussion of any other management options (including specialist referral)
  - contact details for relevant support groups
  - advice on continence products and information about product choice, availability and use
  - advice on skin care
  - advice on how to talk to friends and family

- strategies such as planning routes for travel to facilitate access to public conveniences, carrying a toilet access card<sup>[4]</sup> or RADAR key<sup>[5]</sup> to allow access to 'disabled' toilets in the National Key Scheme.

### **Specific groups**

 Healthcare professionals should take a proactive approach to bowel management for specific groups of people (see box).

### **Box 2 Specific groups**

- people with faecal loading or constipation.
- · patients with limited mobility
- hospitalised patients who are acutely unwell and who develop acute faecal loading and associated incontinence
- · people with cognitive or behavioural issues
- people with neurological or spinal disease/injury resulting in faecal incontinence
- people with learning disabilities
- severely or terminally ill people
- people with acquired brain injury

#### Surgery

- All people with faecal incontinence considering or being considered for surgery should be referred to a specialist surgeon to discuss:
  - the surgical and non-surgical options appropriate for their individual circumstances
  - the potential benefits and limitations of each option, with particular attention to longterm results
  - realistic expectations of the effectiveness of any surgical procedures under consideration.

<sup>[1]</sup> See Section 3 of the Department of Health's <u>'Good practice in continence services' and 'National service framework for older people'</u>.

<sup>&</sup>lt;sup>[2]</sup> See the NICE clinical guideline on referral for suspected cancer.

<sup>&</sup>lt;sup>[3]</sup> For example, pelvic floor re-education programmes might not be appropriate for those with neurological or spinal disease/injury resulting in faecal incontinence.

<sup>[4]</sup> These are available from <u>National Association for Colitis and Crohn's disease (NACC)</u>, <u>Incontactor the Continence Foundation</u>).

<sup>[5]</sup> These are available from RADAR.

## 1 Guidance

The following guidance is based on the best available evidence. The <u>full guideline</u> gives details of the methods and the evidence used to develop the guidance. Recommendations are also summarised in the algorithms (in the <u>full guideline</u>).

## 1.1 Good practice in managing faecal incontinence

- 1.1.1 People who report or are reported to have faecal incontinence should be offered care to be managed by healthcare professionals who have the relevant skills, training and experience and who work within an integrated continence service<sup>[6]</sup>.
- 1.1.2 Because faecal incontinence is a socially stigmatising condition, healthcare professionals should actively yet sensitively enquire about symptoms in high-risk groups (see box 1).

### **Box 1 High-risk groups**

- frail older people
- people with loose stools or diarrhoea from any cause
- women following childbirth (especially following third- and fourth- degree obstetric injury)
- people with neurological or spinal disease/injury (for example, spina bifida, stroke, multiple sclerosis, spinal cord injury)
- people with severe cognitive impairment.
- people with urinary incontinence
- people with pelvic organ prolapse and/or rectal prolapse
- people who have had colonic resection or anal surgery
- people who have undergone pelvic radiotherapy
- people with perianal soreness, itching or pain
- people with learning disabilities.
- 1.1.3 Local clinical teams should work as appropriate with local and national organisations to:
  - raise public awareness of the causes, prevalence and symptoms of faecal incontinence and the resources needed to treat it
  - aid mutual support between people with faecal incontinence
  - decrease the taboo surrounding faecal incontinence
  - encourage people with faecal incontinence to seek appropriate help.
- 1.1.4 All staff working with people with faecal incontinence should be aware of both the physical and the emotional impact this condition can have on individuals and their carers.

- 1.1.5 Healthcare professionals should ensure that people with faecal incontinence and their carers:
  - are kept fully informed about their condition and have access to appropriate sources of information in formats and languages suited to their individual requirements
  - are offered access to or made aware of appropriate support groups (which may include alerting people with faecal incontinence to the possibility of family and friends having similar experiences, or suggesting community groups or more formal organisations). Consideration should be given to the individual's cognition, gender, physical needs, culture and stage of life
  - have the opportunity to discuss assessment, management options and relevant physical, emotional, psychological and social issues. The views, experiences, attitudes and opinions of the individual with faecal incontinence about these issues should be actively sought.
- 1.1.6 When assessing faecal incontinence healthcare professionals should:
  - be aware that faecal incontinence is a symptom, often with multiple contributory factors for an individual
  - avoid making simplistic assumptions that causation is related to a single primary diagnosis ('diagnostic overshadowing').

## 1.2 Baseline assessment

- 1.2.1 Healthcare professionals should ensure that people who report or are reported to have faecal incontinence are offered:
  - a focused baseline assessment to identify the contributory factors before any treatment is considered
  - all appropriate initial management including, where appropriate, condition-specific interventions before any specialised treatment.
- 1.2.2 The focused baseline assessment should comprise:
  - relevant medical history (see <u>table 1</u>)

- a general examination
- an anorectal examination (see <u>table 1</u>)
- a cognitive assessment, if appropriate.
- 1.2.3 People with the following conditions should have these addressed with condition-specific interventions before healthcare professionals progress to initial management of faecal incontinence:
  - faecal loading (see also section 1.7.3)
  - potentially treatable causes of diarrhoea (for example, infective, inflammatory bowel disease and irritable bowel syndrome)
  - warning signs for lower gastrointestinal cancer<sup>[7]</sup>
  - rectal prolapse or third-degree haemorrhoids
  - acute anal sphincter injury including obstetric and other trauma
  - acute disc prolapse/cauda equina syndrome.

## 1.3 Initial management

1.3.1 Healthcare professionals should explain to people with faecal incontinence that a combination of initial management interventions is likely to be needed. The specific management intervention(s) offered should be based on the findings from the baseline assessment, tailored to individual circumstances and adjusted to personal response and preference.

#### Diet, bowel habit and toilet access

- 1.3.2 Healthcare professionals should recommend a diet that promotes an ideal stool consistency and predictable bowel emptying. When addressing food and fluid intake healthcare professionals should:
  - take into account existing therapeutic diets
  - ensure that overall nutrient intake is balanced

- consider a food and fluid diary to help establish a baseline
- advise patients to modify one food at a time if attempting to identify potentially contributory factors to their symptoms (see <u>tables 2 and 3</u>)
- encourage people with hard stools and/or clinical dehydration to aim for at least
  1.5 litres intake of fluid per day (unless contraindicated). Urinary output should be measured where intake is in doubt
- consider the opportunity to screen people with faecal incontinence for malnutrition, or risk of malnutrition<sup>[s]</sup>.
- 1.3.3 Healthcare professionals should address the individual's bowel habit, aiming for ideal stool consistency and satisfactory bowel emptying at a predictable time.
- 1.3.4 A bowel habit intervention should contain the following elements:
  - encouraging bowel emptying after a meal (to utilise the gastrocolic response)
  - ensuring toilet facilities are private and comfortable and can be used in safety, with sufficient time allowed
  - encouraging people to adopt a sitting or squatting position where possible while emptying the bowel
  - teaching people techniques to facilitate bowel evacuation and stressing the importance of avoiding straining.
- 1.3.5 When problems with toilet access are being addressed in any home or healthcare setting:
  - locations of toilets should be made clear to the individual where appropriate
  - equipment to help people to gain access to a toilet should be provided
  - advice should be given to people with faecal incontinence on easily removable clothing to reduce time needed for access

- if a person with faecal incontinence is dependent on others for access to the toilet, help should be readily available
- if appropriate, people with faecal incontinence should be referred to the relevant professionals for assessment of their home and/or mobility.

#### Medication

- 1.3.6 When reviewing medication, healthcare professionals should consider alternatives to drugs that might be contributing to faecal incontinence. (see table 4)
- 1.3.7 Antidiarrhoeal medication should be offered to people with faecal incontinence associated with loose stools once other causes (such as excessive laxative use, dietary factors and other medication) have been excluded. Antidiarrhoeal medication should be prescribed in accordance with the summary of product characteristics.
- 1.3.8 The antidiarrhoeal drug of first choice should be loperamide hydrochloride. It can be used long term in doses from 0.5 mg to 16 mg per day as required. For doses under 2 mg, loperamide hydrochloride syrup should be considered. People who are unable to tolerate loperamide hydrochloride should be offered codeine phosphate or co-phenotrope<sup>[s]</sup>.
- 1.3.9 Loperamide hydrochloride should not be offered to people with:
  - · hard or infrequent stools
  - acute diarrhoea without a diagnosed cause
  - an acute flare-up of ulcerative colitis.
- 1.3.10 When loperamide hydrochloride is used:
  - it should be introduced at a very low dose and the dose should be escalated, as tolerated by the individual, until the desired stool consistency has been achieved
  - it should be taken as and when required by the individual

 individuals should be advised that they can adjust the dose and/or frequency up or down in response to stool consistency and their lifestyle.

### **Coping strategies**

- 1.3.11 During assessment and initial management healthcare professionals should offer people with faecal incontinence advice on coping strategies including:
  - the use of continence products and information about product choice, supply sources and use
  - where to get emotional and psychological support, including counselling or psychological therapy, where appropriate, to foster acceptance and positive attitudes
  - how to talk to friends and family about incontinence and its management
  - strategies such as planning routes for travel to facilitate access to public conveniences, carrying a toilet access card<sup>[10]</sup> or RADAR key<sup>[11]</sup> to allow access to 'disabled' toilets in the National Key Scheme.
- 1.3.12 People with faecal incontinence should be offered:
  - disposable body-worn pads in a choice of styles and designs and disposable bed pads if needed
  - pads in quantities sufficient for the individual's continence needs it is inappropriate to limit the number of pads given
  - anal plugs (for people who can tolerate them)
  - skin-care advice that covers both cleansing and barrier products
  - advice on odour control and laundry needs
  - disposable gloves.
- 1.3.13 The use of reusable absorbent products in the management of faecal incontinence is not generally recommended.

#### Review of treatment

- 1.3.14 After each intervention healthcare professionals should ask the person whether the faecal incontinence has improved. People continuing to experience symptoms should be:
  - involved in discussions about further treatment options (including effectiveness and adverse effects) or alternative coping strategies
  - asked if they wish to try further treatments.
- 1.3.15 The options for long-term management should be considered for people who prefer symptomatic management to more invasive measures (see recommendation in <u>section 1.6</u>).

## 1.4 Specialised management

- 1.4.1 People who continue to have episodes of faecal incontinence after initial management should be considered for specialised management. This may involve referral to a specialist continence service, which may include:
  - · pelvic floor muscle training
  - bowel retraining
  - specialist dietary assessment and management
  - biofeedback
  - electrical stimulation
  - rectal irrigation.

Some of these treatments might not be appropriate for people who are unable to understand and/or comply with instructions. For example, pelvic floor re-education programmes might not be appropriate for those with neurological or spinal disease/injury resulting in faecal incontinence.

1.4.2 Healthcare professionals should consider in particular whether people with neurological or spinal disease/injury resulting in faecal incontinence, who have

- some residual motor function and are still symptomatic after baseline assessment and initial management, could benefit from specialised management (see also <u>section 1.7</u>).
- 1.4.3 Any programme of pelvic floor muscle training should be agreed with the person. A patient-specific exercise regimen should be provided based on the findings of digital assessment. The progress of people having pelvic floor muscle training should be monitored by digital reassessment carried out by an appropriately trained healthcare professional who is supervising the treatment. There should be a review of the person's symptoms on completion of the programme and other treatment options considered if appropriate.

## 1.5 Specialist assessment

- 1.5.1 People with continuing faecal incontinence after specialised conservative management should be considered for specialist assessment, including:
  - anorectal physiology studies
  - endoanal ultrasound; if this is not available, magnetic resonance imaging, endovaginal ultrasound and perineal ultrasound should be considered
  - other tests, including proctography, as indicated.

## 1.6 Long-term management

- 1.6.1 Healthcare professionals should offer the following to symptomatic people who do not wish to continue with active treatment or who have intractable faecal incontinence:
  - advice relating to the preservation of dignity and, where possible, independence
  - psychological and emotional support, possibly including referral to counsellors or therapists if it seems likely that a person's attitude towards and ability to manage and cope with his or her faecal incontinence could improve with professional assistance
  - at least 6-monthly review of symptoms

- discussion of any other management options (including specialist referral)
- contact details for relevant support groups
- advice on continence products and information about product choice, availability and use
- · advice on skin care
- advice on how to talk to friends and family
- strategies such as planning routes for travel to facilitate access to public conveniences, carrying a toilet access card<sup>[10]</sup> or RADAR key<sup>[11]</sup>.

## 1.7 Management of specific groups

- 1.7.1 Pay special attention to <u>recommendation 1.1.6</u> about diagnostic overshadowing.
- 1.7.2 Healthcare professionals should take a proactive approach to bowel management for specific groups of people (see box).

### **Box 2 Specific groups**

- people with faecal loading or constipation
- people with limited mobility
- hospitalised patients who are acutely unwell and who develop acute faecal loading and associated incontinence.
- people with cognitive or behavioural issues
- people with neurological or spinal disease/injury resulting in faecal incontinence
- people with learning disabilities
- severely or terminally ill people
- people with acquired brain injury

### People with faecal loading

- 1.7.3 People in whom acute severe faecal loading is identified as contributing to faecal incontinence should initially be offered a rectally administered treatment to satisfactorily clear the bowel. Often treatment will need to be repeated daily for a few days, depending on tolerance and whether satisfactory bowel clearance is achieved.
- 1.7.4 If rectal interventions are not appropriate or fail to satisfactorily clear the bowel, and bowel obstruction has been excluded as a possible cause, a potent oral laxative should be offered. People should be informed that oral laxatives may cause griping abdominal pain, loose stools and prolonged bowel activity. Toilet access should be ensured.
- 1.7.5 Healthcare professionals involved in the management of faecal incontinence associated with chronic ongoing faecal loading/impaction should aim to reduce the chance of recurrence by recommending a combination of initial management options tailored to the individual (see <a href="recommendation 1.3.1">recommendation 1.3.1</a>). If this fails, the use of orally administered laxatives to promote bowel emptying should be considered. Rectally administered preparations should be used if oral laxatives cause episodes of faecal incontinence and there is a need to produce planned bowel evacuations.

#### People with limited mobility

- 1.7.6 People with limited mobility who continue to have episodes of faecal incontinence after initial management should be offered a regimen that will produce a planned, predicted bowel action when carers are present if needed. This may be achieved by a combination of oral or rectal laxatives and/or constipating agents. This regimen should also consider:
  - toilet access (see recommendation 1.3.5)
  - appropriate disposable products (see <a href="recommendation1.3.12">recommendation1.3.12</a>)
  - that the stool needs to be in the rectum at the time of the planned bowel action.

### People using enteral tube feeding and reporting faecal incontinence

1.7.7 Healthcare professionals should ensure that people with faecal incontinence who are receiving enteral tube feeding have their type and timing of feed modified on an individual basis to establish the most effective way to manage faecal incontinence.

### People with severe cognitive impairment

1.7.8 If baseline assessment and initial management have failed to resolve faecal incontinence, people with confirmed severe cognitive impairment should be referred for a behavioural and functional analysis to determine if there is any behavioural reason for faecal incontinence. Following analysis, people should be offered cause-specific interventions founded on structured goal planning that aim to resolve as well as manage behavioural aspects that may be contributing to faecal incontinence. In cases of severe cognitive impairment, further specialist management of faecal incontinence may be inappropriate.

### People with neurological or spinal disease/injury

- 1.7.9 People with neurological or spinal disease/injury resulting in faecal incontinence who continue to have episodes of faecal incontinence after initial management should be offered a neurological bowel management programme. This aims to achieve a predictable routine and avoid faecal incontinence and severe constipation. Management should involve progressing through the following steps until satisfactory bowel habit is established:
  - ascertaining individual preferences
  - ascertaining premorbid bowel habit, if possible
  - maximising the individual's understanding of normal bowel function and how it has been altered
  - modifying diet and/or administrating rectal evacuants and/or oral laxatives, adjusted to individual response, to attempt to establish a predictable pattern of bowel evacuation

- consideration of digital anorectal stimulation for people with spinal cord injuries or other neurogenic bowel disorders
- consideration of manual/digital removal of faeces, particularly for people with a lower spinal injury, if there is a hard plug of faeces in the rectum, presence of faecal impaction, incomplete defaecation, an inability to defaecate and/or all other bowelemptying techniques have failed to achieve bowel emptying and continence within a time acceptable to the individual<sup>[12]</sup>.
- 1.7.10 Healthcare professionals should discuss the following management options with people unable to achieve reliable bowel continence after a neurological bowel management programme:
  - coping and long-term management strategies for symptomatic individuals (see recommendations in sections <u>1.3.11</u> and <u>1.6</u>)
  - rectal irrigation if appropriate
  - other surgical options (including stoma) if faecal incontinence or the time taken for bowel emptying imposes major limits on their lifestyle.

### People with learning disabilities

1.7.11 People with severe learning disabilities may have had faecal incontinence from childhood. Others may experience faecal incontinence for the first time in adulthood. It is essential that these individuals follow the same initial care pathway as other people with faecal incontinence. They may require additional support during assessment and management to achieve equal outcomes.

#### Severely or terminally ill people

1.7.12 Healthcare professionals should consider a faecal collection device for people in intensive care settings and people receiving palliative care with faecal incontinence and associated loose stools.

# 1.8 Surgery

- 1.8.1 All people with faecal incontinence considering or being considered for surgery should be referred to a specialist surgeon to discuss:
  - the surgical and non-surgical options appropriate for their individual circumstances
  - the potential benefits and limitations of each option, with particular attention to longterm results
  - realistic expectations of the effectiveness of any surgical procedures under consideration.
- 1.8.2 People with a full-length external anal sphincter defect that is 90° or greater (with or without an associated internal anal sphincter defect) and faecal incontinence that restricts quality of life should be considered for sphincter repair. They should be given a realistic expectation of what this operation can achieve and information about possible adverse events, in both the short and long terms.
- 1.8.3 People with internal sphincter defects, pudendal nerve neuropathy, multiple defects, external sphincter atrophy, loose stools or irritable bowel syndrome should be informed that these factors are likely to decrease the effectiveness of anal sphincter repair.
- 1.8.4 People undergoing anal sphincter repair should not routinely receive a temporary defunctioning stoma.
- 1.8.5 People undergoing anal sphincter repair should not receive constipating agents in the postoperative period and should be allowed to eat and drink as soon as they feel able to.
- 1.8.6 A trial of temporary sacral nerve stimulation should be considered for people with faecal incontinence in whom sphincter surgery is deemed inappropriate<sup>[13]</sup>. These may be patients with intact anal sphincters, or those with sphincter disruption. In those with a defect, contraindications to direct repair may include

- atrophy, denervation, a small defect, absence of voluntary contraction, fragmentation of the sphincter or a poor-quality muscle.
- 1.8.7 All individuals should be informed of the potential benefits and limitations of this procedure and should undergo a trial stimulation period of at least 2 weeks to determine if they are likely to benefit. People with faecal incontinence should be offered sacral nerve stimulation on the basis of their response to percutaneous nerve evaluation during specialist assessment, which is predictive of therapy success. People being considered for sacral nerve stimulation should be assessed and managed at a specialist centre that has experience of performing this procedure.
- 1.8.8 If a trial of sacral nerve stimulation is unsuccessful, an individual can be considered for a neosphincter, for which the two options are a stimulated graciloplasty or an artificial anal sphincter<sup>[14]</sup>. People should be informed of the potential benefits and limitations of both procedures. Those offered these procedures should be informed that they may experience evacuatory disorders and/or serious infection, either of which may necessitate removal of the device. People being considered for either procedure should be assessed and managed at a specialist centre with experience of performing these procedures. If an artificial anal sphincter is to be used, there are special arrangements that should be followed, as indicated in NICE interventional procedures guidance 66<sup>[14]</sup>.
- 1.8.9 People who have an implanted sacral nerve stimulation device, stimulated graciloplasty or an artificial anal sphincter should be offered training and ongoing support at a specialist centre. These people should be monitored, have regular reviews and be given a point of contact.
- 1.8.10 Antegrade irrigation via appendicostomy, neo-appendicostomy or continent colonic conduit may be considered in selected people with constipation and colonic motility disorders associated with faecal incontinence.
- 1.8.11 A stoma should be considered for people with faecal incontinence that severely restricts lifestyle only once all appropriate non-surgical and surgical options, including those at specialist centres, have been considered.

Individuals should be informed of the potential benefits, risks and long-term effects of this procedure. Individuals assessed as possible candidates for a stoma should be referred to a stoma care service.

See Section 3 of the Department of Health's 'Good practice in continence services' and 'National service framework for older people'.

<sup>[1]</sup> See the NICE clinical guideline on referral for suspected cancer.

<sup>[8]</sup> See the NICE clinical guideline on nutrition support.

<sup>&</sup>lt;sup>[9]</sup> Prescribers should check the summary of product characteristics (SPC) for current licensed indications. Informed consent is needed when using outside the licensed indications. This should be discussed and documented in the notes.

These are available from <u>National Association for Colitis and Crohn's disease</u> (NACC), <u>Incontact or the Continence Foundation</u>.

<sup>[11]</sup> These are available from RADAR.

<sup>[12]</sup> See advice from the National Patient Safety Agency (NPSA 2004).

<sup>[13]</sup> See NICE interventional procedures guidance on sacral nerve stimulation.

<sup>[14]</sup> See also NICE interventional procedures guidance on stimulated graciloplasty.

## 2 Notes on the scope of the guidance

NICE guidelines are developed in accordance with a <u>scope</u> that defines what the guideline will and will not cover.

### How this guideline was developed

NICE commissioned the National Collaborating Centre for Acute Care to develop this guideline. The Centre established a Guideline Development Group (see <a href="appendix A">appendix A</a>), which reviewed the evidence and developed the recommendations. An independent Guideline Review Panel oversaw the development of the guideline (see <a href="appendix B">appendix B</a>).

There is more information about <u>how NICE clinical guidelines are developed</u> on the NICE website. A booklet, 'How NICE clinical guidelines are developed: an overview for stakeholders, the public and the NHS' is <u>available</u>.

## 3 Implementation

The Healthcare Commission assesses the performance of NHS organisations in meeting core and developmental standards set by the Department of Health in 'Standards for better health', issued in July 2004. Implementation of clinical guidelines forms part of the developmental standard D2. Core standard C5 says that national agreed guidance should be taken into account when NHS organisations are planning and delivering care.

NICE has developed tools to help organisations implement this guidance (listed below).

- Implementation advice on how to put the guidance into practice and national initiatives which support this locally
- Audit criteria to monitor local practice
- Costing tools:
  - costing report to estimate the national savings and costs associated with implementation
  - costing template to estimate the local costs and savings involved.

## 4 Research recommendations

The Guideline Development Group has made the following recommendations for research, based on its review of evidence, to improve NICE guidance and care of people with faecal incontinence in the future.

## 4.1 Pelvic floor muscle training

What is the value of pelvic floor muscle training in preventing and treating obstetric-related faecal incontinence?

### Why this is important

Obstetric-related faecal incontinence is a distressing condition which may occur early after childbirth. Previous obstetric injury is also a major cause of faecal incontinence in older women, so reducing risk would have important benefits for both young and old people. Obstetric risk factors relate not just to sphincter disruption, but also to pelvic floor damage, and there is reason to believe that improving pelvic and sphincter strength before potential injury may be beneficial. Equally, early intervention post partum may help reduce the well recognised risk of delayed-onset faecal incontinence in women.

There is no standardisation of what pelvic floor muscle training should comprise. There is also no evidence base on whether treatment before potential injury (that is, labour) serves a protective role. This study will require the interaction of obstetric, colorectal and physiotherapy services across primary and secondary care.

## 4.2 Patient-rated outcomes

The development of a valid and reliable tool to measure patient-rated outcomes including symptom severity and quality of life for people with faecal incontinence.

#### Why this is important

Research into and treatment of faecal incontinence is hampered by the lack of a valid and reliable tool that has been refined through iterative piloting and consultation stages. Such a tool would enable standardisation of outcome measures with which to compare results of

interventions, allowing the effectiveness of interventions to be genuinely compared and accurately assessed.

Qualitative review for this guideline has highlighted the paucity of information on patients' views and the crudeness of current evaluation of symptoms and outcomes. By involving users, healthcare providers and qualitative researchers in the design of a tool, the most relevant outcomes (to all groups) could be measured, including symptom severity and quality of life. Each group would bring different perspectives to the tool, ensuring that all relevant topics are covered and that the tool is useful to all groups.

## 4.3 Self-care educational programmes

Would a self-care educational programme for patients and carers improve outcomes (symptom severity and quality of life) for people with faecal incontinence?

### Why this is important

Qualitative evidence suggests that mutual support groups improve quality of life for people with faecal incontinence. Evidence also suggests that people with faecal incontinence should benefit from improved access to healthcare options, that information about management and treatment options is scarce, and that the taboo surrounding faecal incontinence hinders help-seeking behaviour. Addressing these issues would allow patients to be involved in tailoring of individual care plans.

A self-care group programme providing integrated education and support covering topics such as support networks, coping strategies, and identification and provision of suitable products and treatments may aid practical care and improve both physical and psychological outcomes. It would provide community-based healthcare, involving healthcare professionals including continence specialist clinicians and clinical psychologists, and would integrate with social care.

This type of self-care programme may reduce the demand on secondary care. The views of those attending may shape future health/social care by reducing the number of admissions to residential care because of faecal incontinence.

# 4.4 Bowel management programme

Does a bowel management programme for older people in care homes improve the outcomes of faecal incontinence and constipation? Does the programme improve perceptions of quality of care for the individual with faecal incontinence and the carer?

### Why this is important

Over 50% of older people in care homes suffer from bowel-related problems. This is the cause of much anxiety and discomfort for patients, and adds to the carer burden. Moreover, with the UK's ageing population, this problem will increase with time. Little research has been done on effective bowel care in this population, and care is expensive, with laxatives, pads and carer time all contributing to the overall cost.

A management programme for this population may provide a way of enhancing the quality of life of people with faecal incontinence and their carers, and improve overall healthcare.

## 4.5 Specialist assessment

What is the prognostic value of physiological assessment in defining the outcome of surgery to treat faecal incontinence?

#### Why this is important

It is currently hard to predict which people will benefit from surgical treatment for faecal incontinence. Developing an improved selection procedure would reduce unnecessary procedures, reducing costs and improving care pathways for people with faecal incontinence.

Clinical assessment could be compared with full physiological and structural assessment in people referred for specialist assessment in whom surgery is contemplated. This would allow a more accurate correlative description of the relationship between symptoms and physiology or structure. This in turn would allow a better selection procedure to be developed. Following people through surgery and over a long-term follow-up period would allow the prognostic value of certain physiological/structural abnormalities in defining surgical outcome to be evaluated. Long-term outcome of certain surgical procedures could also be investigated.

This research question would be best answered by a multicentre study based on a network of NHS secondary care sites.

# 5 Other versions of this guideline

## 5.1 Full guideline

The full guideline, <u>Faecal incontinence</u>: the management of faecal incontinence in adults contains details of the methods and evidence used to develop the guideline. It is published by the National Collaborating Centre for Acute Care.

# 5.2 Information for the public

NICE has produced information for the public explaining this guideline.

We encourage NHS and voluntary sector organisations to use text from this information in their own materials.

## 6 Related NICE guidance

- Irritable bowel syndrome. NICE clinical quideline 61 (2008).
- Injectable bulking agents for faecal incontinence. <u>NICE interventional procedure guidance</u> 210 (2007).
- Urinary incontinence: the management of urinary incontinence in women. <u>NICE clinical guideline 40</u> (2006).
- Percutaneous endoscopic colostomy. NICE interventional procedure guidance 161 (2006).
- Stimulated graciloplasty for faecal incontinence. <u>NICE interventional procedure guidance</u> 159 (2006).
- Artificial anal sphincter implantation. <u>NICE interventional procedure guidance 66</u> (2004).
- Sacral nerve stimulation for faecal incontinence. <u>NICE interventional procedure guidance 99</u> (2004).
- Circular stapled haemorrhoidectomy. NICE interventional procedure guidance 34 (2003).

# 7 Updating the guideline

NICE clinical guidelines are updated as needed so that recommendations take into account important new information. We check for new evidence 2 and 4 years after publication, to decide whether all or part of the guideline should be updated. If important new evidence is published at other times, we may decide to do a more rapid update of some recommendations.

## **Appendix A: The Guideline Development Group**

### **Professor Christine Norton (GDG Chair)**

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**Project Manager** 

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### Mr David Wonderling

Senior Health Economist

## **Appendix B: The Guideline Review Panel**

The Guideline Review Panel is an independent panel that oversees the development of the guideline and takes responsibility for monitoring adherence to NICE guideline development processes. In particular, the panel ensures that stakeholder comments have been adequately considered and responded to. The Panel includes members from the following perspectives: primary care, secondary care, lay, public health and industry.

#### Mr Peter Robb - Chair

Consultant ENT Surgeon, Epsom & St Helier University Hospitals and The Royal Trusts

#### Mrs Jill Freer

Director of Patient Services, Rugby PCT

#### Mr John Seddon

Patient representative

#### Mr Mike Baldwin

Head of Health Technology Appraisals, Sanofi-Aventis

#### **Dr Christine Hine**

Consultant in Public Health (Acute), South Gloucestershire PCT

# **Appendix C: The algorithms**

The <u>full guideline</u> contains a care pathway and algorithms.

## About this guideline

NICE clinical guidelines are recommendations about the treatment and care of people with specific diseases and conditions in the NHS in England and Wales.

The guideline was developed by the National Collaborating Centre for Acute Care. The Collaborating Centre worked with a group of healthcare professionals (including consultants, GPs and nurses), patients and carers, and technical staff, who reviewed the evidence and drafted the recommendations. The recommendations were finalised after public consultation.

The methods and processes for developing NICE clinical guidelines are described in <u>The guidelines manual</u>.

We have produced <u>information for the public</u> explaining this guideline. Tools to help you put the guideline into practice and information about the evidence it is based on are also <u>available</u>.

### Changes after publication

June 2012: minor maintenance

October 2013: minor maintenance

#### Your responsibility

This guidance represents the view of NICE, which was arrived at after careful consideration of the evidence available. Healthcare professionals are expected to take it fully into account when exercising their clinical judgement. However, the guidance does not override the individual responsibility of healthcare professionals to make decisions appropriate to the circumstances of the individual patient, in consultation with the patient and/or guardian or carer, and informed by the summary of product characteristics of any drugs they are considering.

Implementation of this guidance is the responsibility of local commissioners and/or providers. Commissioners and providers are reminded that it is their responsibility to implement the guidance, in their local context, in light of their duties to avoid unlawful discrimination and to have regard to promoting equality of opportunity. Nothing in this guidance should be interpreted in a way that would be inconsistent with compliance with those duties.

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