



# Faecal incontinence in adults: management

Clinical guideline

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## Your responsibility

The recommendations in this guideline represent the view of NICE, arrived at after careful consideration of the evidence available. When exercising their judgement, professionals and practitioners are expected to take this guideline fully into account, alongside the individual needs, preferences and values of their patients or the people using their service. It is not mandatory to apply the recommendations, and the guideline does not override the responsibility to make decisions appropriate to the circumstances of the individual, in consultation with them and their families and carers or guardian.

All problems (adverse events) related to a medicine or medical device used for treatment or in a procedure should be reported to the Medicines and Healthcare products Regulatory Agency using the <u>Yellow Card Scheme</u>.

Local commissioners and providers of healthcare have a responsibility to enable the guideline to be applied when individual professionals and people using services wish to use it. They should do so in the context of local and national priorities for funding and developing services, and in light of their duties to have due regard to the need to eliminate unlawful discrimination, to advance equality of opportunity and to reduce health inequalities. Nothing in this guideline should be interpreted in a way that would be inconsistent with complying with those duties.

Commissioners and providers have a responsibility to promote an environmentally sustainable health and care system and should <u>assess and reduce the environmental impact of implementing NICE recommendations</u> wherever possible.

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This guideline is the basis of QS54.

## Overview

This guideline covers assessing and managing faecal incontinence (any involuntary loss of faeces that is a social or hygienic problem) in people aged 18 and over. It aims to ensure that staff are aware that faecal incontinence is a sign or a symptom, not a diagnosis.

It aims to improve the physical and mental health and quality of life of people with faecal incontinence.

### Who is it for?

- Healthcare professionals
- · Commissioners and providers
- Care workers
- People with faecal incontinence and their families and carers

## 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% to 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.

## 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. See the
  Department of Health and Social Care's National service framework for older people.
- 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 conditionspecific interventions before healthcare professionals progress to initial management of faecal incontinence:
  - faecal loading (see also <u>section 1.7.3</u>)
  - potentially treatable causes of diarrhoea (for example infective, inflammatory bowel disease and irritable bowel syndrome)
  - warning signs for lower gastrointestinal cancer. See the <u>NICE guideline on the</u> recognition and referral of suspected cancer.
  - 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. For example, pelvic floor re-education programmes might not be appropriate for those with neurological or spinal disease/injury resulting in faecal incontinence.

#### 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 or RADAR key 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 2).

#### **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 long-term results

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_	realistic expectations of the effectiveness of any surgical procedures under consideration.	

## Recommendations

People have the right to be involved in discussions and make informed decisions about their care, as described in <a href="NICE's information on making decisions about your care">NICE's information on making decisions about your care</a>.

Making decisions using NICE guidelines explains how we use words to show the strength (or certainty) of our recommendations, and has information about prescribing medicines (including off-label use), professional guidelines, standards and laws (including on consent and mental capacity), and safeguarding.

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 full guideline).

## 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. See the <a href="Department of Health and Social Care's National service framework for older people">Department of Health and Social Care's National service framework for older people</a>.
- 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.

- 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

- 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, conditionspecific 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 table 1)
  - 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 <u>section 1.7.3</u>)
  - potentially treatable causes of diarrhoea (for example, infective, inflammatory bowel disease and irritable bowel syndrome)
  - warning signs for lower gastrointestinal cancer. See the <u>NICE guideline on the</u> recognition and referral of suspected cancer.
  - · 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 1 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. See the <u>NICE guideline on nutrition</u> support for adults.
- 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 <u>table</u> 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 (SPC).
- 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. Prescribers should check the SPC for current licensed indications. Informed consent is needed when using outside the licensed indications. This should be discussed and documented in the notes. For guidance on safe prescribing of opioids (such as codeine phosphate) and managing withdrawal, see <a href="NICE's guideline on medicines associated with dependence or withdrawal symptoms">NICE's guideline on medicines associated with dependence or withdrawal symptoms</a>.
- 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

- 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 or RADAR key 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 section 1.7).
- 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

- 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 or RADAR key.

## 1.7 Management of specific groups

1.7.1 Pay special attention to <u>recommendation 1.1.6</u> about diagnostic overshadowing.

Healthcare professionals should take a proactive approach to bowel management for specific groups of people (see box 2).

#### **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 <u>recommendation 1.3.12</u>)
  - 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 bowel-emptying techniques have failed to achieve bowel emptying and continence within a time acceptable to the individual.
- 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 <u>section 1.3.11</u> and <u>section 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 long-term 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 degrees 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. See the <a href="NICE">NICE interventional procedures guidance on sacral nerve stimulation for faecal incontinence</a>. 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 2 options are a stimulated graciloplasty or an artificial anal sphincter. See also the NICE interventional procedures guidance on stimulated graciloplasty for faecal incontinence. 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 the NICE interventional procedures guidance on artificial anal sphincter implantation.
- 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.

## Recommendations for research

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.

## 1 Pelvic floor muscle training

What is the value of pelvic floor muscle training in preventing and treating obstetricrelated 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.

#### 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.

## 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 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.

## 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.

Faecal incontinence in adults: management (CG49) This research question would be best answered by a multicentre study based on a network of NHS secondary care sites.

## Appendix: The algorithms

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

## Finding more information and committee details

To find NICE guidance on related topics, including guidance in development, see the <u>NICE</u> topic page on digestive tract conditions.

For full details of the evidence and the guideline committee's discussions, see the <u>full</u> <u>guideline</u>. You can also find information about <u>how the guideline was developed</u>, including details of the committee.

NICE has produced tools and resources to help you put this guideline into practice. For general help and advice on putting our guidelines into practice, see resources to help you put NICE guidance into practice.

## **Update** information

#### Minor changes since publication

**May 2022:** We added a link to NICE's guideline on medicines associated with dependence or withdrawal symptoms in the section on medication.

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