FI Patient
Decision Aid

Helping you make decisions about treatment for faecal incontinence

The Faecal Incontinence Patient Decision Aid Statement of Ownership and Pledge

We, the Steering Committee, declare our independent ownership of the Patient Decision Aid (PDA), a comprehensive educational tool for people living with faecal incontinence (FI). This Patient Decision Aid aims to help patients make informed decisions about their treatment options and engage in shared decision making with their healthcare providers (HCPs).

To ensure the FI Patient Decision Aid can continue to benefit as many people with FI as possible, we agree to the free access, use and sharing of the tool by Medtronic, the organisations that we represent and the wider medical community.

This document cannot be used for commercial purposes.

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Introduction

This FI Decision Aid was made for people who have been diagnosed with FI and are thinking about what to do next.

You may have had treatment for FI before, and/or made lifestyle changes, but if these measures aren't giving you the support you need, there are other options you may want to consider. This Decision Aid will look at the choices available and help you decide on a way forward.

This Decision Aid was co-created with, reviewed and approved by medical experts and patient advocates to ensure that the information provided is accurate and unbiased. It was developed from funding by Medtronic. All content was co-created and validated by an independent steering committee of expert healthcare professionals and representatives from patient advocacy groups. For more information, see page 3.

The information presented on this document is for information purposes only. It is not intended to replace a consultation with a healthcare professional.

Introduction

If you have been diagnosed with faecal incontinence (FI) because you aren't able to control when you pass stool (also called poo, waste or faeces), you may have questions about what you can do to bring it under control and what support is available to help you face the challenges in your daily life.

Aside from the direct problems FI may cause, there are many choices related to your lifestyle and treatment that you may not feel fully prepared to make.

This Decision Aid has been created to help you make those decisions, and help you find the treatment that works best for you and your lifestyle.

- In section 1 you can **learn more about faecal incontinence**, what it is and how it affects people.
- In section 2 we'll guide you through the main **treatment options**, their pros and cons and how they work.
- In section 3 we'll provide **tips for choosing** the option that's right for you.
- In section 4 we'll outline ways of finding **further support** for living with FI.

You can work through the booklet at your own pace using these icons to move around the pages or return to this contents page.

Contents

What is FI?

FI, or faecal incontinence, is defined medically as the ongoing uncontrolled loss of solid or liquid stool for at least 3 months.[1] This means passing stool when you don't want to.

What the medical definition doesn't include is the huge emotional impact that FI can have on a person. Many people living with FI experience social isolation, loss of self-confidence and depression.[2] These feelings may stem from the stigma and taboo around 'private' or 'dirty' parts of the body, feeling embarrassed by the smell, sound or sight of unwanted stool, and self-isolating at home to avoid public embarrassment.

01 About FI

Some people are too embarrassed to tell even their friends, family or doctor about FI and try to find ways they can adapt around their condition. This has meant that the number of people who actually live with FI is probably higher than the number of people who are treated for it.[1]

In fact, FI is very common, affecting up to 1 in 12 adults. It can affect men and women of any age, and although it is more common in women and those aged over 60, it is not a normal part of ageing and it can often be managed successfully.[3]

There's no need to be embarrassed about talking to your doctor or nurse. Healthcare professionals deal with FI all the time, and are there to help you.

Myth buster

There are lots of misconceptions about FI. Here we'll look at some myths and learn more about the reality of FI.

Myth 1 | FI is rare

Reality:

While it's not easy to accurately estimate the number of people with FI (many people 'suffer in silence' and don't report it), a 2024 review put the figure at between 7 and 15% of the population, with higher rates in older adults and women.[4]

Myth 2 | FI only affects older people

Reality:

Again, although people aged over 60 are more likely to have FI, it can occur at any age. In fact, it's estimated that 1 in 20 people under 60 are living with FI.[3]

Myth 3 | FI only affects women

Reality:

Even though more women than men have FI, men can be affected by it too. And while pregnancy, labour and surgical treatment for gynaecological issues like endometriosis raise the risk of FI, there are in fact many different causes of FI, some of which can affect either sex.[1,4]

Myth 4 | You can overcome FI through willpower

Reality:

FI is caused by physical changes in your body – no amount of willpower or positive thinking can fix them. Avoiding stress can help address some of the symptoms, but the core treatments for FI are lifestyle changes, dietary changes, medication and medical procedures.[1]

Myth 5 | FI is untreatable

Reality:

While no single treatment has been shown to be 100% effective for 100% of people, there are many treatments available that can significantly reduce symptoms. If one treatment isn't enough, there are often plenty of alternatives and different combinations to try. Have a look at pages 18 to 26 to see an overview of the options.

Myth 6 | The only way to overcome FI is surgery

Reality:

Many people see significant improvements in their FI symptoms through lifestyle changes and physiotherapy. Surgery is usually the last option to be explored, as it carries its own risks and drawbacks, so it is only considered when all other options have been thoroughly tried first.[1,4,5]

Myth 7 | People with FI have cognitive dysfunction

Reality:

This is simply not true. While cognitive dysfunction (e.g. dementia) can affect a person's ability to get to a toilet in time, it doesn't cause FI.[6]

Myth 8 | People with FI are just lazy or dirty

Reality:

FI is a medical condition that can be brought under control by a clear treatment plan and management strategies. People with FI deserve to be treated with the dignity, kindness and respect shown to anyone with a medical condition.

What causes FI?

Faecal incontinence is not a disease in itself. It is a symptom of other things that may be happening in the body, or be the result of treatments you are receiving for other health issues, including:[1]

- Diarrhoea
- Constipation (e.g. impacted bowel leading to overflow)
- Side effects from medication(s) you are taking
- Anal sphincter injury or weakness (e.g. injury from childbirth)
- Surgeries to the rectum or anus
- Structural disorders of the pelvic floor (e.g. descending perineum)
- Nerve disorders (e.g. multiple sclerosis or Parkinson's disease)
- Inflammatory conditions (e.g. Crohn's disease, ulcerative colitis)
- Radiotherapy (e.g. radiation treatment for cancer)

Doctors generally categorise FI into 3 main types:[1]

Urge incontinence	Faecal seepage	Passive incontinence
When you can't hold in stool even if you try	Liquid stool that leaks out without warning after a bowel movement	Passing stool with gas without realising

There can be overlap between these different types of FI. If you're not sure which kind you have, you may want to keep a diary of your bowel habits for 1–2 weeks and share it with your healthcare team. This can help them build up a clearer picture of exactly what is happening.

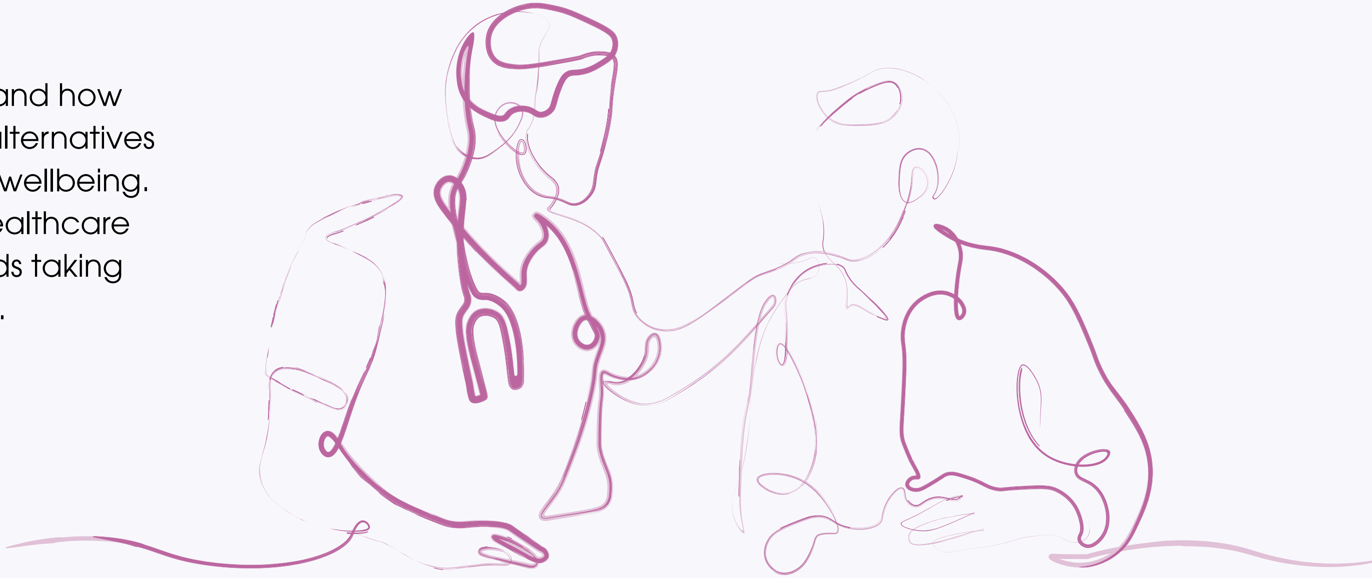
You can find an example of a bowel habit diary on page 40 ›

Living with FI

A lot of people living with FI try to find ways to manage it on their own, and don't tell a doctor about it. This may be because:[7]

- They think nothing can be done to help them
- They don't realise there are services available to help, or they don't know how to access those services
- They are embarrassed or ashamed
- They don't think FI is 'serious' enough to see a doctor about

Sometimes people get so used to living with FI and how they work around it, that they stop looking for alternatives and don't realise the effect it is having on their wellbeing. However, there are a number of ways that a healthcare professional can help – and the first step towards taking back control of your FI is to start talking about it.



01 About FI

It can be very helpful for your GP to get a full picture of how FI impacts you, your life and your wellbeing, so take a moment to think about the different ways it affects you, e.g.:

- Do you limit your time spent away from home?
- Have you had to change or leave your job, or ask for extra support from your employer?
- Do you research toilet facilities before going somewhere new (toilet mapping)?
- Have you had to change holiday plans, or have you made a decision about how or where to travel based on access to toilets?
- Do you say no to social events in case you have an FI emergency?

Going into an appointment with these thoughts in mind may help you have more meaningful talks with members of your healthcare team.

Your FI healthcare team

You don't have to manage FI on your own – there is a whole range of medical professionals who may be involved in providing care. Who you will see will depend on:

- Where you live – different areas may have different processes
- How you accessed treatment – e.g. whether you went to your GP with FI, or developed FI as a result of or after treatment for another health condition

When multiple specialists are involved in a care plan, it's called a multidisciplinary team or MDT.

The MDT involved in managing FI may vary between countries and different health centres. Ask your healthcare team for more information about your personal care.

People who may be in your FI healthcare team:

Your family doctor	(also called your 'GP' or 'primary care doctor') is often the first person you see about your symptoms. They may have referred you to a specialist who then confirmed your diagnosis and prescribed you treatment. Your family doctor may be responsible for monitoring your health between follow-up appointments with a specialist.
A gastroenterologist	is a doctor specialising in the digestive system who can prescribe treatments and assess your progress in managing FI.
An oncologist	specialises in cancer. If FI happens because of cancer treatment, you may be referred by the oncologist as part of your treatment plan.
An endocrinologist	specialises in hormones and hormone-related health conditions like diabetes or hyperthyroidism that may cause FI.[8]
A neurologist	specialises in disorders of the nervous system and the brain, such as multiple sclerosis.
A gerontologist	specialises in the care of older people.

Depending on where you live and what your medical needs are, you may also see:

A dietician	– a specialist in nutrition who can help you understand if anything in your diet may be triggering FI symptoms and who can make recommendations for changes to what you eat and drink.
A specialist nurse, nurse practitioner or continence team nurse	– these are highly trained nurses who specialise in managing specific conditions such as FI. For example, you may be seen by a specialist pelvic floor nurse who provides treatment.
A physiotherapist	– a specialist in how the human body moves, who can teach you exercises to strengthen your pelvic floor muscles and gain better control of those muscles.
A counsellor or mental health professional	if FI is causing you distress, you may want to speak to a qualified counsellor, therapist or psychiatrist who can help you work through your emotions.
Community-based healthcare professionals	include occupational therapists and social workers and can be an important source of support for living with FI.
Dermatologists	specialise in skin and may recommend products to manage any skin damage caused by incontinence.

If your FI isn’t fully controlled with medical treatment(s), lifestyle changes and self-management – or if there is an anatomical cause such as a muscle tear, rectal prolapse or fistula – you may be referred to a **colorectal surgeon**. These surgeons specialise in bowel-related conditions, and surgery may be considered if more conservative treatments aren’t enough.

02 Understanding your treatment options

How FI is treated

The treatment for FI can vary depending on the cause of your symptoms and how severe they are. Often, a combination of approaches is needed.[1,4]

FI can be managed with treatment, but not everyone will see the same benefits and it may take some time for you to feel your FI is improving.

TIP: Keeping a diary of changes in your bowel habits might help you notice the effects of treatment sooner.

You can find an example of a bowel diary here ›

Note: The treatment options available for management of FI may vary between countries and different health centres. Ask your healthcare team for more information about your personal treatment plan.

You may need to try a number of different treatment options, starting with simple lifestyle changes and, if that doesn't succeed, working through to more invasive procedures.[1,4] This is what is known as a conservative approach. It means that you will only move on to the later stages of the treatment pathway (e.g. specialised treatment) after trying the earlier options over an agreed period of time.[1]

As a general rule, treatment goes through up to 6 different steps:[5]

1. Lifestyle/dietary changes

2. Pelvic floor exercises

3. Medication

4. Non-surgical interventions

5. Less invasive surgery

6. More invasive surgery

It's important to remember, though, that this is not a one-way process. You will still need to keep up lifestyle changes alongside medication, for example. Your healthcare team will be able to give you more information about the specifics of your treatment plan, but most people can expect to follow a set of steps similar to that above. However, this may not reflect everyone's experience and there is no 'correct' order or timeframe over which treatment should take place.

You may also feel at any stage that you do not want to try more invasive procedures or any treatment. This Decision Aid can help you weigh up your options at each step and make the right decision for you at the time – you can always change your mind or explore other options if circumstances change.

If your FI has a clear anatomical cause, like a muscle tear, fistula or prolapse that can be repaired, your healthcare team may recommend surgical treatment sooner rather than later.[1]

What to expect from treatment

No single treatment will 'cure' FI overnight. It's often a gradual process of making changes to your lifestyle and diet, and adding in exercises, medications and other interventions as needed.

If you decide you do want treatment, you will need to take on the responsibility of sticking to the treatment plan that you and your healthcare team agree together. They can't make lifestyle changes or take medications for you, so it is up to you to do your part.

02 Understanding your treatment options

STEP 1

Lifestyle changes

Your healthcare team may recommend that you make some changes to your lifestyle. These can include:[1,5]

- Dietary changes
  - Increasing dietary fibre intake – fibre supplements, e.g. psyllium, may be given to bulk out watery stools
  - Reducing caffeine, alcohol, fatty foods, fructose, lactose
  - Staying well hydrated by drinking plenty of water
- Improving bowel habits
  - Try changing meal times, meal sizes, avoiding spicy food
  - Aim for smaller, regular bowel movements at predictable times

- Losing weight if you are overweight
- Stopping smoking
- Using absorbent products (e.g. incontinence pads)
- Skin care products for people at risk of incontinence-associated dermatitis (IAD)
- Exercise such as jogging yoga

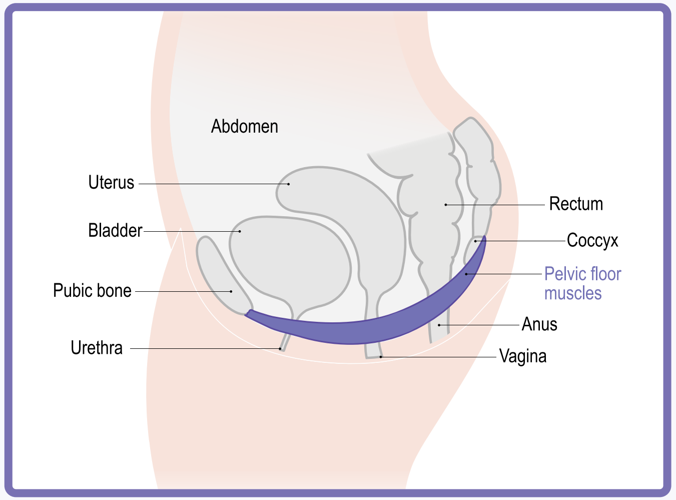
STEP 2

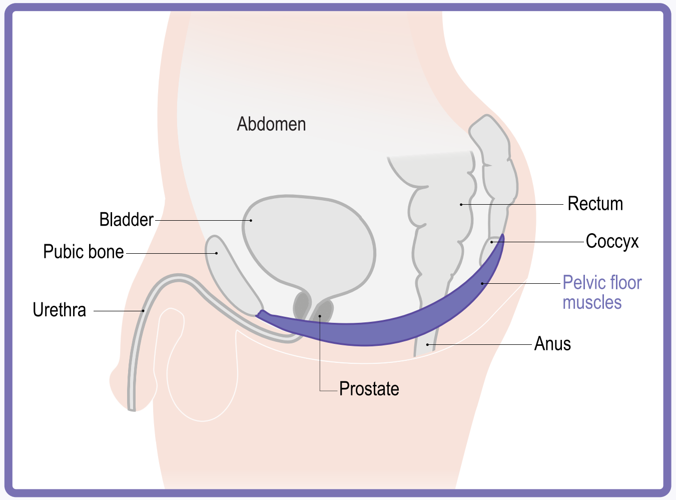
Pelvic floor exercises

One potential cause of FI is weakness in the muscles that control bowel movements,[4] so part of your treatment plan may include exercises and/or use of specialised medical devices to help strengthen those muscles and enable you to have more control.[1,9]

Pelvic floor rehabilitation has been shown to be a very useful treatment for FI. It is an umbrella term for a variety of different approaches that may be used alone or in combination.[9]

These exercises and devices also help to re-train your body to recognise when you need to use the bathroom and might include:





STEP 2

Pelvic floor exercises

Electrostimulation

This is when small devices are placed in or near the anus or vagina which deliver a very small electrical signal to the nerves that control the muscles in the pelvic floor.[1] The aim is to increase the strength and endurance of the anal sphincter muscle – the ring of muscle that controls the opening of the anus.[9]

Volumetric rehabilitation – also called discrimination training

This is typically done with specialised balloons that are inflated with air or water to simulate the sensation of a full rectum. Each time the procedure is done, the volume of air or water in the balloon is decreased which helps you recognise the sensation with a smaller volume of stool. The idea is that this will give you more time to get to a toilet.[9]

Biofeedback therapy (BFT)

This is training to help you be more aware of your bowel function. In some cases this may include the use of electronic devices that give you a visible or audible signal during an activity (e.g. squeezing your anal sphincter muscle).[1,5] BFT devices let you know how strongly the muscles are contracting, and you can use that information to carry out your pelvic floor exercises more effectively.[9]

Achieving the best possible pelvic floor strength and control is crucial before considering more invasive procedures.

STEP 3

Medications

Medications used to help treat FI

Medications used to help treat FI aim to slow down the bowel and improve the consistency of stool, making it less liquid and easier to control.[4]

There are a few medications that are designed to help stop diarrhoea, and you may be offered one of these if diarrhoea is a problem for you.[1,4] The most commonly prescribed medication is loperamide, although codeine or co-phenotrope (diphenoxylate + atropine) may be used in some cases.[4,5]

Constipation can also be related to FI. Different types of laxative might be used to help clear any blockages and prevent overflow (where liquid stool built up behind a blockage in the bowel overflows).[1,4]

STEP 4

Non-surgical interventions[1,5]

If lifestyle changes and medications aren´t enough to control FI, more invasive interventions might be considered. These include:

Trans-anal irrigation – the rectum (the tube inside the anus) is washed out with water. This can be done in a clinic or at home.

Anal inserts – these act like barriers, physically preventing stool from leaking out of the anus. You can put these in and take them out as needed.

Posterior tibial nerve stimulation (PTNS) – a small electrical current is sent up the posterior tibial nerve that runs from your ankle to your pelvis. This is done in an outpatient clinic by healthcare professionals.

STEP 5

Less invasive surgery[1,5]

If all other treatments, exercises, interventions and lifestyle adaptations have failed to control FI, surgery may be an option for some people. All surgery carries some risk, so you may want to talk it over with your friends, family and healthcare team before deciding to go ahead.

If there is a clear anatomical cause for FI, such as a rectal prolapse or fistula, this will be addressed first.[4]

Surgical procedures can help improve symptoms by restoring anatomy and/or improving the function of the muscles around the anus.[4] Surgical techniques that may be used include:

Sacral neuromodulation (SNM) – a pacemaker-like device is implanted just under the skin in the upper buttock. These devices use a small electrical current to stimulate the sacral nerves at the base of the spine. Implanting an SNM device is done in 2 separate surgeries: first to place a temporary implant to see if it has an impact on FI symptoms; then, if there has been an improvement in FI symptoms, a permanent device may be implanted.[10]

Sphincteroplasty – surgery to repair torn or weakened anal sphincter muscles, which happens to some people when they give birth.[1]

STEP 6

More invasive surgery[1,5]

Some people may be advised to have more advanced surgery if previous steps in the treatment plan haven't brought their FI symptoms under control.

An example of a more invasive surgery could be a **faecal diversion surgery, such as colostomy:** surgery to create an opening from the bowel out to the abdomen (a stoma), where waste is collected in a bag. Stomas may be temporary or permanent.[10]

Many people are understandably nervous about this option, because of concerns about how to manage disposal of their stool and worries about how they might be perceived by others. But for some, particularly if they have been housebound because of their FI, it can significantly improve their quality of life.[1,5]

What does a good treatment plan look like for you?

A treatment plan can help you get a clear picture of your current situation, so you can identify areas that you would particularly like to improve.

Earlier on, we asked you to reflect on the aspects of your life that are affected by FI and the changes you have made to your daily routine to fit around your health. Here you can record how much FI impacts your life on a scale from 0 – 10, where 0 is no impact and 10 is very significant impact:

	0	1	2	3	4	5	6	7	8	9	10
Ability to do your job well											
Ability to pursue your hobbies											
Ability to spend quality time with your family and friends											
Ability to enjoy your sex life											
Quality of sleep											
Ability to carry out day-to-day tasks (e.g. shopping)											
Ability to travel											
Emotional wellbeing (e.g. Do you feel embarrassed, judged by others etc. and does that bother you?)											
Mental health (e.g. depression or anxiety)											

You may want to share your answers with your healthcare team so they can better understand your needs and priorities.

Talking to your healthcare team about treatment options

Now that you know how FI affects you, you may want to start a conversation with your healthcare team about next steps.

It isn't always easy to talk openly about FI or to lead conversations about your care, but you can build your confidence with a little planning and preparation. It can help to ask yourself some questions about how you want to proceed.

The first question to ask yourself is:

How involved do you want to be in decisions about your treatment?

Not everyone feels comfortable taking the lead in discussions about their care, but you should at least feel able to share your thoughts and preferences. Your healthcare team are the experts in medicine, and it's perfectly okay to let them guide your choices – just remember that you are the only expert in your needs and experiences, and your voice needs to be heard.

You can find out more about shared decision-making with your healthcare provider in the appendix at the end of this booklet.

03 Choosing a treatment

Key questions to ask your healthcare team

You, your doctors, nurses and any other health professionals involved in managing your FI are all part of the same team, working together to the same goal. If you're struggling in any way, whether it's FI symptoms, treatment or something in your personal life that is making things harder for you, be sure to let them know.

Appointments

If attending appointments is an issue for you, you could ask the healthcare team if you could use remote/telemedicine appointments rather than coming into the clinic, or ask for an appointment at specific times of day (e.g. later in the day if FI symptoms are worse in the morning).

You can also ask to bring someone with you to appointments if you would like. A friend or relative can help with practical things like transport, as well as taking notes about what was said.

Treatments

Before deciding on a treatment plan, it could be helpful to ask your healthcare team:

- Are there any treatments that are not available in this area, or that have very long waiting lists?
- What are the long-term effects of this treatment?
- What side effects could there be and how should I manage them?
- Who do I get in touch with to report any problems?
- How do I give feedback about how I am getting on with my treatment?

Talking to family and friends about your FI and treatment options

As well as your healthcare team, you may want to speak to your family and friends about the ways they can support you.

You might feel embarrassed about your FI but your loved ones can be a real source of emotional and practical support for you. You could ask your healthcare team about how to explain FI to someone who doesn’t fully understand it. You can go into as much or as little detail as you feel comfortable with. You could also share this document with them.

Keep in mind that even if someone wants to help you, they might not know how. Take the time to consider the ways in which you might want support. When discussing treatment options with loved ones, it can be helpful to think about what impact the various options might have on your life, and how much support your friends and family would be able to offer, for example:

- If the treatment requires travel to and from a healthcare facility
- Childcare or other responsibilities if you need to stay in hospital overnight

03 Choosing a treatment

Examples might include:

- Helping you travel to medical appointments
- Booking appointments
- Attending medical appointments with you to take notes and check that everyone has understood what was said
- Finding appropriate incontinence products
- Finding resources and information online
- Making time to talk about your treatment options
- Doing household chores like grocery shopping if you are worried about going out in public
- Listening to your experiences

Knowing when to try something new

As we've explored in section 2, your healthcare team will recommend taking a conservative approach to treatment that includes keeping up good habits like improving your lifestyle. For many people, the early treatment steps can bring a welcome improvement in their FI symptoms, and they don't need to move on to more advanced treatment options.

When to consider trying a new treatment

You can't expect an overnight improvement in your FI, but if you have followed your current treatment plan closely and still haven't seen enough of an improvement in your symptoms and/or the effect they have on your life, it may be time to think about next steps. The more advanced options tend to be more invasive, but can give you that extra support to bring FI under control.

If you decide you want to move forward with a more advanced treatment, you should make time to speak to your healthcare team to discuss the options available. Bear in mind that they may recommend staying with your current treatment plan if they feel you could benefit from it further – not all of the more advanced treatment options are suitable in every case.

Choosing a treatment

What to ask your healthcare team

If your healthcare team agree that it's time to try something new, you will need to discuss some important subjects.

What matters most to you when considering a treatment choice? There are no right or wrong answers; it's about finding the right plan of action for you. You can ask as many questions as you need to feel confident about trying a new treatment. For example, you might want to ask:

- How long does the treatment last?
- How often does the treatment need to be repeated?
- Where will you receive the treatment, e.g. at home, in a clinic or in hospital?
- How quickly will you get relief from FI symptoms?
- What sort of improvement can you expect from this treatment?
- What do we know about how well the treatment works? Have there been clinical trials?
- What does the treatment procedure involve?
- How invasive is the treatment?
- What is the risk of complications from the treatment?
- What are the potential side effects of the treatment?
- How will side effects be managed?
- Is there a waiting list for the treatment? What would it cost to have it done privately?

03 Choosing a treatment

STEP 1

Lifestyle changes

- Diet and exercise
- Change bowel habits
- Weight loss
- Quit smoking
- Use incontinence products
- Use skincare products

STEP 2

Pelvic floor exercises

- Electrostimulation
- Volumetric rehabilitation
- Biofeedback therapy

STEP 3

Medications

- Slow down bowel activity
- Change stool consistency
- Treat diarrhoea
- Treat constipation

STEP 4

Non-surgical interventions

- Trans-anal irrigation
- Anal inserts
- Posterior tibial nerve stimulation (PTNS)

STEP 5

Less invasive surgery

- Sacral neuromodulation (SNM)
- Sphincteroplasty

STEP 6

More invasive surgery

- Faecal diversion surgery (colostomy /ileostomy)

Which step of treatment are you currently at?

How satisfied do you feel with your current treatment?

Would you like to talk to your doctor about trying something new?

Notes: ....

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Finding support for living with FI

You don't have to face FI alone

Ask your healthcare team if there are any local people experienced with FI you could speak to or patient groups you could join where you can talk to other people living with FI. They will have advice on making the most of life with FI.

Support

If there's nothing local, or you prefer to go online, you can also find national groups like:

- Crohn's and Colitis UK
- Continence Product Advisor
- Age UK
- Guts UK
- Bladder and Bowel UK
- World Federation of Incontinence and Pelvic Problems (WFIPP)

5 top tips for FI self-care

Tip #1: Look after your skin

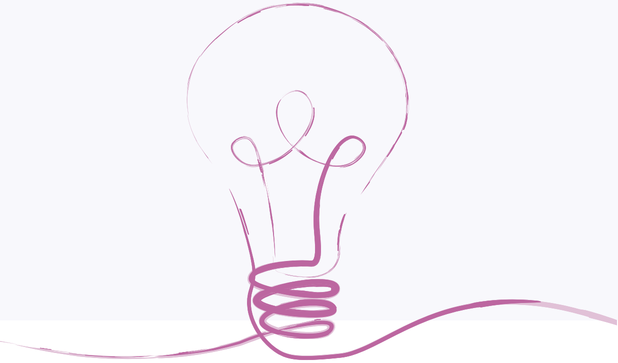
Stool is slightly acidic, so if it stays on the skin for too long it can cause skin problems. Take action to prevent skin damage by:[12]

- Changing out of any soiled clothes as soon as you can
- Washing skin with soap and water, and patting dry gently with a towel rather than rubbing
- Using a moisturiser and barrier cream (also called an emollient) to protect your skin. Avoid products that contain alcohol or perfume, as these can irritate your skin
- Asking your healthcare team about which products they would recommend and how you can access them

Tip #2: Get a RADAR, URGENT or Just Can't Wait card

Many organisations for bowel and bladder disorders offer small cards that you can show to staff in shops, bars, restaurants and other public places to gain access to their toilets. These cards enable you to communicate quickly and discreetly that you have a medical need to use the toilet urgently.

The RADAR key is available from Disability Rights UK, and enables you access to locked public toilets all around the UK.[13] You can also speak to your healthcare team as they may be able to provide one.



Tip #3: Toilet mapping

It can be helpful to know exactly where publicly accessible toilets are wherever you go. Look online for specialised toilet map services in your area.

In the UK, you could try The Great British Toilet Map at toiletmap.org.uk

For much of Europe, mapcomplete.org/toilets shows where the nearest public restrooms are.

Tip #4: Be prepared

Having an emergency kit with you can help you feel more confident about travelling or going out in public. Items you might want to include in your kit might be:

- Clean clothes to change into
- Incontinence pads or underwear
- Wet wipes that can be easily disposed of
- Waterproof bags to take soiled clothes away with you

Tip #5: Try to de-stress

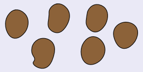
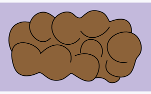
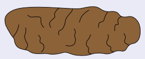
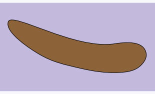
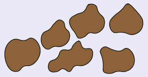
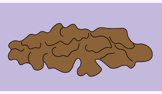
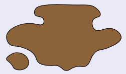
There are many ways to reduce stress and anxiety and feel more positive. You might like to try these ideas to see what works for you:

- Meditation and mindfulness
- Doing regular, gentle physical activities like yoga, walking or gardening
- Doing something you enjoy
- Talking with friends

Monitoring your health

It can be helpful to keep a diary or notes about your health, so you can see if there are any patterns to your symptoms, track your progress with a new treatment plan, and give your healthcare team a fuller picture of how FI affects your life.

One useful tool your healthcare team may use is the Bristol Stool Chart:

Type 1		**Separate hard lumps, like nuts**
Type 2		**Sausage-shaped but lumpy**
Type 3		**Like a sausage but with cracks on the surface**
Type 4		**Like a sausage or snake, smooth and soft**
Type 5		**Soft blobs with clear-cut edges**
Type 6		**Fluffy pieces with ragged edges, a mushy stool**
Type 7		**Watery, no sold pieces**

You may want to keep track of the type of stool you experience each day, and whether it changes over time. This is a good way to communicate clearly with your healthcare team, with everyone using the same terms.

Keeping an FI diary

You can use a diary or journal to record two things:

1. Any time you pass stool and how it was
2. What you are eating, drinking and doing each day that might be affecting your bowel

The more information you can provide the better – this enables you to identify if there are any patterns (e.g. eating a certain food that tends to lead to bloating and type 6 stools), and also enables your healthcare team to more accurately assess both the impact of FI on your life and the impact of a particular treatment plan on your FI.

Support

Here is an example of a bowel diary. You can also search online for diaries created by patient organisations or health services, which you can print at home for everyday use.

Date		**Did you strain a lot? Yes/No**	
Time of day		**Any medications? What type? How many?**	
Stool type		**Need to help with finger/pressure? Yes/No**	
Time spent on toilet		**Difficulty wiping clean? Yes/No?**	
Pain/discomfort/ bleeding		**Itchy around anus? Yes/No?**	
Stool/gas leakage Yes/No		**Anxious/nervous? Yes/No? Reasons why?**	
Feeling bloated? Yes/No		**Deferment time (how long were you able to 'hold' before you needed to go to the bathroom)? Less than a minute/ 1–3 mins/3–5 mins/5–10 mins/10+ mins**	
Any other comments?			

Appendix

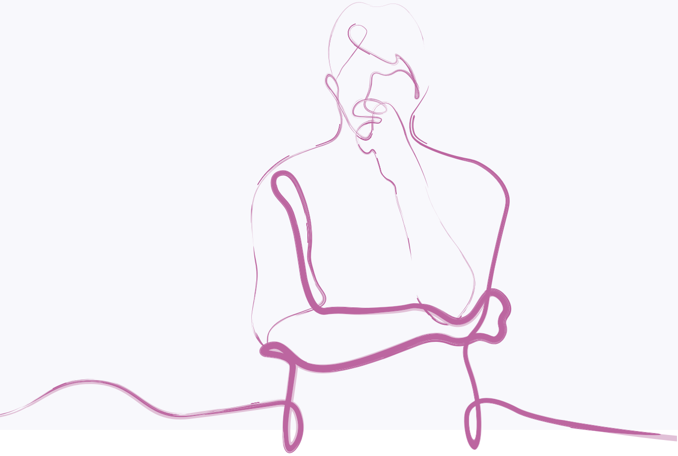
What is shared decision-making (SDM)?

Shared decision-making is a process in which doctors and patients work together to reach a decision about their healthcare.[14] It involves talking about tests and treatments and choosing options based on both the medical information and the individual's needs and preferences. Healthcare professionals are the experts on the medical evidence and patients are the experts on what matters most to them.[15]

How does SDM work?

Shared decision-making with your healthcare team should make you feel comfortable, well informed and confident about your choices. When you make shared decisions with your healthcare team, you have:

1. The right to be involved and supported in your healthcare
2. A conversation focused on your specific needs, whether it is in person, by phone or video call
3. The right to be listened to
4. The right to be given high-quality sources of information, such as links to official healthcare providers' websites, appropriate patient organisations, or relevant professional guidelines and quality-assured patient decision aids, plus time and support to make decisions[14]
5. The understanding that all adults can make decisions
6. The option of making decisions with the help of family and friends
7. Confidence that everyone should be supported



Appendix

What are the benefits of SDM?

Information alone may not be enough to support you when you are making a decision about your health.[16] Some people may want to be more involved in making decisions about their health and care but find it difficult to understand their medical needs and the treatments involved, or feel nervous about asking questions or expressing concerns.

Shared decision-making gives you an active role in your care so you can understand the risks, benefits and possible side effects of different treatment options. People who are more involved in their own healthcare decisions are more satisfied with the care they receive.[17]

Shared decision-making also benefits people by:[14]

- Giving you the opportunity to discuss and share information so you have a good understanding of the different options.
- Empowering you to make decisions about the treatment and care that is right for you at that time. This includes choosing to continue with their current treatment or choosing no treatment at all.
- Giving you the choice about how much you want to participate in decision-making.

Appendix

What if I don't want to make shared decisions?

Many people want to play an active role in making decisions about their treatment and ensure the options match their needs and values.[18] Others may feel overwhelmed or confused by treatment decisions and prefer to trust their doctor will make the right decision for them.

Some individuals may not want to take part in making decisions at a particular time, such as choosing a treatment plan. Some decisions are not urgent, even when an illness is serious. You don't always have to make decisions about your treatment right away. Some people may need more time to think about their options and discuss them with family and friends or to gather information before they make their decision.[19]

Decisions about your FI treatment should be based on what is best for you, according to your circumstances and values.[20] Part of what is best for you is how comfortable you feel making decisions about your care. You don't have to participate in shared decision-making if you don't want to.

Your healthcare provider should consider your personal preferences for how much you want to be involved in making decisions about your treatment and tailor your care accordingly.

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