

# Bowel incontinence

### and urgency

This information is for adults with Crohn's or Colitis who experience bowel incontinence or urgency. There is very little evidence for managing bowel incontinence and urgency in children with Crohn's or Colitis. But many of the same things may be helpful for children.

This information can help you understand:

- What causes bowel incontinence and urgency
- How bowel incontinence and urgency can affect people with Crohn's or Colitis
- How bowel incontinence and urgency can be managed

It also provides you with some tips to help you live well with bowel incontinence or urgency.

If you have a stoma and are having a problem with high output, see our information on <u>Living with a stoma</u>.

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### **Key facts**

- Bowel incontinence is when you pass liquid or solid poo without meaning to.
- Urgency is the sudden intense feeling of needing to poo and having to rush to get to the toilet.
- Bowel incontinence and urgency affect up to 7 in every 10 people with Crohn's or Colitis.
- You are more likely to experience bowel incontinence during a flare-up. But it can also occur during remission. Urgency is common during remission.
- Bowel incontinence and urgency can be sensitive issues that can have a real impact on your daily life.
- Tell your IBD team or GP if you are experiencing problems with bowel control. There are ways of managing these.

### What is bowel incontinence?

**Bowel incontinence** is when you pass liquid or solid poo without meaning to. There are two main types of bowel incontinence:

- Urge incontinence: you feel a strong need to poo and are unable to hold it in until you reach a toilet.
- Passive incontinence: you are unaware that you have passed poo.

Some people will experience both urge and passive incontinence.



Some people will have incontinence from time to time. For others it might happen every day. It can also happen at night.

People may describe their bowel incontinence as:



### What is urgency?

**Urgency** is the sudden intense feeling of needing to poo and having to rush to get to the toilet.

People may describe their urgency as:





### How common are bowel incontinence and urgency?

Bowel incontinence affects about 1 in 10 people in the general population at some point in their life.

Bowel incontinence is more common in people with Crohn's or Colitis than in the general population. Studies estimate that it affects up to 7 in every 10 people with Crohn's or Colitis at some point.

Urgency is also a common symptom of Crohn's and Colitis. In one study nearly 70% (7 in every 10) people reported having urgency.

It is likely that many people do not report having problems with bowel control. So, it could be even more common than studies estimate.

You are more likely to experience bowel incontinence or urgency during a flare-up. But they can also occur during remission (when your symptoms are under control). Bowel incontinence affects at least 10% (1 in 10) people in remission. Urgency affects up to 66% (6 in 10) people in remission. It is more common in people who have **proctitis**, a **perianal fistula** or an **ileo-anal pouch** (a J-pouch).

Bowel control problems in people with Crohn's or Colitis are also more common:

- With increasing age, although they can affect people of any age
- In people who have had the condition for more than 15 years
- In those with more severe symptoms



### Effects on everyday life

Urgency and bowel incontinence can be a sensitive issue that can have a real impact on your daily life. People who experience bowel incontinence may:

- Feel extreme embarrassment and even ashamed
- Worry about having an 'accident' (accidental bowel leak or poo) in public
- Need to take time off work, school, or college
- Feel anxious about finding a toilet when they are out
- Cancel social events and avoid going out
- Feel reluctant to travel
- Be afraid to leave their home, leading to isolation
- Feel anxious, low, or depressed
- Worry about it getting worse as they get older

But there are ways of managing and treating bowel control problems. So, make sure you ask for help from your GP or IBD team. It's important to remember that:

- Bowel incontinence is not something to feel ashamed of.
- There is a range of treatments and ways to manage urgency and bowel incontinence.
- It will not usually go away on its own. Most people need help to manage urgency or bowel incontinence.





### **Causes of urgency and bowel incontinence**



The bowel is the largest part of your gut. It consists of two sections, the small bowel and the large bowel. You might also hear them called the small intestine and the large intestine. The large bowel consists of the colon and the rectum. The rectum is the part that stores poo.

At the end of your rectum is the **anus**. This is the opening where poo comes out of your bottom. The **anal canal** connects the rectum to the anus. The way your body controls when you fart (pass wind) and poo is complicated. It involves:

- The ability of the rectum to keep poo in
- The muscles of the bowel, rectum, and anus
- Nerve signals from the bowel to the brain

If any of these systems are not working as well as they should, you may experience urgency or bowel incontinence.

The most common causes of bowel control problems for people with Crohn's or Colitis are:



#### Diarrhoea

Diarrhoea (passing a looser poo more often than is normal for you) is a key symptom of Crohn's and Colitis. It can be difficult for the rectum to hold in liquid poo, especially when it happens often. So, urgency and bowel incontinence can develop.

#### Inflammation of the bowel

In a healthy gut, the muscles in the bowel move poo slowly along the bowel. In people with Crohn's or Colitis the bowel can become inflamed, which makes it more sensitive. This can make the rectum more active, pushing poo out as soon as it arrives. Inflammatory changes to the muscles and nerves of the gut can persist once inflammation dies down. This can cause problems with bowel control even when disease is not active.

#### Muscle damage

Muscles in your bottom (anus) work to keep poo in until you are ready to pass it. These muscles are known as your anal sphincter. If these muscles are damaged, you may have less control over passing wind, and liquid or solid poo. In people with Crohn's or Colitis, these muscles can become damaged by:

- An anal fistula
- Pouch surgery
- Perianal surgery



Damage to the muscles can also be due to other causes not related to Crohn's or Colitis. These include childbirth, surgery, or piles (haemorrhoids).



This diagram shows the position of the muscles around the anal canal where poo travels. The pelvic floor muscles also help you control when you pass pee, poo, and wind.

#### Nerve damage

Nerves control both the sensations from the bowel, and the anal sphincter muscles. Ongoing inflammation due to Crohn's or Colitis can affect the nerves in the gut lining. This damage can make the bowel more sensitive and affect control of the anal sphincter.

#### Constipation

Some people with Crohn's or Colitis have constipation. Constipation is when it becomes difficult to poo, and you may not have a poo for several days or even weeks. When you do it may be hard and lumpy. Liquid or solid poo can build up in the large bowel and become packed together. Liquid poo can then sometimes leak around the packed poo. This is sometimes called overflow diarrhoea. You might not be aware of this leakage, as there will be no urge to have a poo.

#### Perianal fistula

A fistula is when a narrow tunnel develops that connects an organ to another part of your body. A perianal fistula connects the anal canal or rectum to the surface of the skin near your bottom. Pus, blood, or poo can drain from the fistula opening. A perianal fistula can also cause damage to the anal sphincter. See our information on **Fistulas** for more details.



### Managing bowel incontinence and urgency

Most of the evidence for managing bowel control problems comes from people with bowel incontinence. There is less evidence for the management of urgency, but it is generally managed in the same way as incontinence.

There are several things that you can try to help manage your bowel incontinence. Some of these you may be able to do by yourself. For others you may need help from a healthcare professional. For many people, these <u>initial approaches</u> will help to improve bowel control. If these first steps do not help, you may need more <u>specialised</u> <u>management</u>.

#### **Initial approaches**

#### Getting your Crohn's or Colitis under control

A key part of managing urgency and bowel incontinence in people with Crohn's or Colitis is getting your condition as well controlled as possible. Reducing inflammation in the bowel and reducing diarrhoea or constipation can help improve these symptoms.

#### Food and drink

Changing what you eat and drink can help to reduce diarrhoea or constipation in some people. This in turn can help reduce urgency and bowel incontinence. You could try using a food diary or app to find out if any foods affect your symptoms.

It is still important to eat a healthy, varied diet that gives you all the nutrients you need to stay well. Find out more about healthy eating in our **Food** information.

Some types of food or drink stimulate the muscles in the large bowel. This increase in muscle activity pushes poo through more quickly, which can cause diarrhoea. Foods or drinks that might make diarrhoea worse in people with or without Crohn's or Colitis include:

• Caffeine



- Alcohol
- Artificial sweeteners
- Liquorice

If you're constipated, you could try:

- Eating regular, healthy meals.
- Gradually increasing the amount of fibre you eat.
- Eating plenty of wholegrain foods, fruit, and vegetables.
- Choosing fruits or fruit juices like apples, pears, plums, apricots, raisins, peaches, or prunes. These are high in a natural laxative called sorbitol.
- Drinking plenty of fluid.

For more details about this, see our information on <u>Diarrhoea and constipation</u>. You can find out more about eating and drinking to help with symptoms in our <u>Food</u> information.

#### Access to a toilet

Making sure that you have easy access to a toilet is an important part of managing urgency and bowel incontinence. For example, you might ask your employer to move your workstation closer to a toilet. Or you might discuss toilet access with your child's school to ensure swift access when needed.

See <u>Tips for living well with bowel incontinence</u> for suggestions about toilet access when you are out and about.

#### Making sure your bowel is empty

To help you empty your bowel completely and at a predictable time, you could try:

Having a poo after a meal. Whenever you swallow food or drink a wave of pressure moves through your gut towards your bottom. For some people with Crohn's or Colitis, this wave can be very strong, and they need to poo during or immediately after eating. You can use this response to help make sure your bowel is empty. This may make you less likely to need a poo, or have an accident, later in the day.



• Using a sitting or squatting position when you poo. Sometimes when the bowel is inflamed it can be difficult to be sure it is empty when you have been to the toilet. This can be a particular problem for people with an <u>ileo-anal pouch</u>. Sitting on the toilet with your feet up on a footstool and pushing from your tummy muscles (rather than holding your breath and pushing) can help to empty your bowel. For more details about this, see our information on <u>Diarrhoea and constipation</u>.

#### Anti-diarrhoeal medicine

If other approaches do not work, your GP or IBD team may suggest trying anti-diarrhoeal medicine. These slow down your bowel. This means that food takes longer to pass through your gut and your body absorbs more fluid from the bowel. So your poo becomes firmer and you need to poo less often. Loperamide is a commonly used anti-diarrhoeal medicine.

Always check with your IBD team before taking anti-diarrhoeal medicine.

- Do not use anti-diarrhoeal medicine if you are in a flare-up. This can lead to a serious complication called <u>toxic megacolon</u> (widening or swelling of the colon that may cause perforation).
- You may not be able to take anti-diarrhoeal medicines if you have a narrowing of the bowel called a <u>stricture</u> (a narrowing of a section of the bowel).

Read more about the medicines that can be used to relieve diarrhoea and constipation.

#### **Continence services**

Some NHS continence clinics offer services for people with bowel incontinence. You may be able to refer yourself to your nearest service, or your GP or IBD team may need to refer you. Depending on the service, they can provide access to free advice, teach you pelvic floor exercises and bowel retraining. They can also arrange supply of free continence pads and give you additional support.



#### **Specialised tests**

Your GP or a member of your IBD team may refer you for specialised tests to see why you are having difficulty controlling your bowel. These might include:

- Endoanal ultrasound. This is a scan to look at your anal sphincter. It will be able to tell if the anal sphincter muscles are damaged.
- Anorectal physiology tests. These tests are to assess the function of your anus and rectum. They provide information about the nerves and muscles that control the bowel.
- Magnetic resonance imaging or proctography. These allow doctors to look at the rectum and the pelvic floor muscles. They can also check for a blockage in your rectum.
- Balloon expulsion test. This can identify any problems with how you poo.

#### **Specialist management**

A continence specialist may recommend the following treatments.

#### **Bowel retraining**

Bowel retraining is a treatment programme that involves:

- Making changes to improve the consistency of your poo (how hard or soft it is). This will often involve changing what you eat and drink.
- Creating a regular routine for going to the toilet.
- Practicing "holding on" if you have urgency.
- Learning ways to help you fully empty your bowels.

#### Pelvic floor muscle exercises

Your pelvic floor muscles help support your bowel, bladder, and the womb in people who have one. These muscles run from your pubic bone at the front to the base of your spine at the back. They help you control when you pass pee, poo, and wind. These muscles can become weaker with age or after childbirth. Pelvic floor exercises can help strengthen the



muscles around your bottom that you use to open and close your bowels. There is some evidence that this can help with managing bowel incontinence.

A physiotherapist or specialist nurse will show you how to do the exercises. It is important to learn to do pelvic floor exercises in the right way. And to check from time to time that you are still doing them correctly.

#### **Biofeedback therapy**

Biofeedback therapy is a type of bowel retraining. It may sometimes be used with pelvic floor exercises. Biofeedback involves placing a small sensor device in your bottom while you are doing the exercises. The device provides information about how well the muscles are working while you're doing the exercises. Biofeedback therapy is not yet widely available. Ask your IBD team or continence specialist if they provide this service. Or they may be able to refer you to another hospital or centre where it is available.

#### **Electrical stimulation**

**Sacral nerve stimulation** is a type of electrical stimulation. It can be used for people with weak sphincter muscles. Electrodes are inserted under the skin in the lower back and connected to a pulse generator. The generator releases pulses of electricity that stimulate the sacral nerves. The sacral nerves are in your lower back. This causes the muscles of the anal sphincter and pelvic floor to work more effectively. At first, the pulse generator is located outside your body. If the treatment works, it will be implanted under the skin in your back.

A review of six clinical trials found that sacral nerve stimulation can improve continence in some people. But it does not work for everyone. These trials did not specifically include people with Crohn's or Colitis. Very small studies suggest that sacral nerve stimulation works well for people with Crohn's or Colitis. We need more studies to confirm this.

Side effects of sacral nerve stimulation can include pain and infection at the site of the implants.

**Tibial nerve stimulation** is another type of electrical stimulation therapy. A fine needle is inserted near a nerve just above the ankle and an electrode is placed on the foot. A mild



electric current is passed through the needle to stimulate the nerves that control bowel function. It is a new treatment for bowel incontinence and we are not sure how well it works in people with Crohn's or Colitis.

#### Surgery

Surgery is usually only considered if other treatments have not helped. But it is a treatment option for people with Crohn's or Colitis, depending which part of the bowel is affected. See our information on <u>Surgery for Crohn's or Colitis</u> for more details.

### Tips for living well with bowel incontinence

The following section contains tips and suggestions to help you manage urgency or bowel incontinence.

### Ask for help!

If you are experiencing bowel incontinence or urgency, speak to your GP or a member of your IBD team.

People can be reluctant to talk about problems controlling their bowels. Some people find it very upsetting or embarrassing. It is important to get medical advice if you experience urgency or bowel incontinence. Often it can be managed so that it does not interfere with your everyday life.

In one study, only 4 out of 10 people who experienced bowel incontinence reported asking for help. Reasons people gave for not seeking help included:

- They did not think anything could be done
- They did not know who to ask
- They felt too embarrassed or ashamed
- They did not think that healthcare professionals would understand or be interested
- They were not aware of specialist continence services



#### **Continence products**

Continence products can be useful as a short-term measure. But they do not deal with the underlying problem. They are not a long-term solution on their own.

If you have bowel incontinence, continence products can help stop you soiling your clothes. You may be able to get them free on the NHS from a <u>continence clinic</u> or your District Nurse. Or ask your GP surgery for more information about continence products available. You can also buy them online or from a pharmacy.

Bladder and Bowel UK have more information on continence products and services.

The <u>Continence Product Advisor</u> gives independent and evidence-based advice on how to choose and use continence products.

#### **Pads and underwear**

Continence products such as disposable pads re often used in people with faecal incontinence. Disposable pads can help to contain and soak up liquid poo and prevent your skin from getting sore. They can be useful for mild bowel incontinence. Disposable pull-on pads and washable underwear are also options.

#### Anal plug

Using an anal plug is another option for managing incontinence. An anal plug is a foam plug that you insert into your bottom to prevent leaks. You can keep it in for up to 12 hours. Many people find that it is uncomfortable or irritating. You must take the plug out before you have a poo, so it is not suitable if you need to go to the toilet often. Speak to your IBD team if you are thinking of using an anal plug, as they are not suitable for everyone.

#### **Skin care**

Bowel incontinence can cause sore skin around your bottom. Frequent washing and wiping of your bottom can also irritate the skin. Keeping the skin clean and dry is the most effective way to reduce sore skin.



The following tips may help prevent sore skin:

- Change pads or other absorbent products as soon as possible after any bowel leakage.
- Moist toilet paper, damp cotton wool or moist toilet wipes can be more comfortable than dry toilet paper. Some toilet wipes contain alcohol and other chemicals which can irritate the skin. Try to choose alcohol-free brands or products for sensitive skin.
- Whenever possible, wash around your bottom after you have had a poo. Avoid using flannels and sponges as they can be rough and are difficult to keep clean. Avoid using disinfectants or antiseptics as these can sting and you may be sensitive to the chemicals in them. Plain warm water is best.
- Avoid using products with strong perfume. Instead use non-scented soap or a norinse cleanser. These cleansers avoid the need for soap and water, which may dry the skin.
- Dry the area with soft toilet paper or a soft towel. Be very gentle and pat rather than rub. If your skin is very sore, you could try using a hairdryer on a low heat setting to dry the skin.
- You can use barrier products to protect the skin. Barrier products act to reduce the skin's contact with poo. They usually contain substances such as zinc oxide or dimeticone. There is currently not enough evidence to show that one product works better than another. Barrier products are available in different forms such as creams, ointments, and wipes.

Check before using them as some people are allergic to some of the ingredients, such as lanolin. Use a little at a time, as too much can stop the skin from breathing and can make the area sweaty and uncomfortable. Always make sure you wash off the old layer before applying more.

• Try to allow the air to get to the area. Wear cotton underwear and avoid synthetic material to allow the skin to breathe. Try not to wear tight-fitting clothes such as tights and tight trousers.



• If you use incontinence pads, try to make sure that no plastic touches your skin, and you use pads with a soft surface.

If your skin continues to feel sore or it is broken, talk to your doctor or IBD team.

#### **Getting rid of smells**

If you are worried about smells, you may wish to try odour neutralisers. These help to get rid of smells rather than just mask them. Products available include room sprays and toilet deodorisers.

#### **Managing stress and anxiety**

Bowel incontinence or the fear of it happening can cause embarrassment, stress, anxiety, and concern. This can lead to a vicious circle where the more you worry the worse it feels. Talking about how you are feeling can help. You might try talking to your GP, IBD team or to a close friend or family member. Your medical team will want to know about the effect that any problems with bowel control may be having on your wellbeing. So, it's important to let them know if you're struggling with stress, anxiety, or depression.

Struggling with your mental health can make it more difficult to manage your Crohn's or Colitis. Learn more about what you can do to improve your mental wellbeing and how to get the help you need in our information on <u>Mental health and wellbeing</u>.

"Managing bowel incontinence has been a very real challenge for me, particularly with a few "accidents" at work. Being prepared and identifying what some of the causes could be, has helped me to try to manage and prevent future issues."

**Andy,** Living with Colitis



#### **Getting out and about**

Planning ahead can give you more confidence to be away from home. The following are suggestions that may help you manage bowel incontinence when you are out and about.

#### Emergency kit:

Some people find it useful to carry a supply of:

- Pads
- Underwear
- Alcohol-free wipes
- Tissues
- Nappy disposal bags for soiled clothes or pad disposal
- A small mirror to check you're clean
- Clothes pegs to keep your clothes out of the way if you need both hands to get clean
- A neutraliser spray to disguise smells
- Barrier cream or ointment if you are prone to sore skin

You may also wish to keep a change of clothes at work or in your car, just in case of any accidents.

"I have a number of little strategies, such as carrying a little bag with all my emergency supplies, to help me live a good and full life alongside the condition I have, and its unpredictability."

#### Gillian,

#### Living with Crohn's

**Clothing:** Wear trousers or skirts that are easy to undo, perhaps with an elasticated waist or a zip or Velcro instead of buttons. Darker colours may disguise leaks more easily. The <u>**Continence Product Advisor**</u> has more information on clothing and adjustments that can help with managing incontinence.



**Can't Wait Card:** Members of Crohn's & Colitis UK get a 'Can't Wait' Card'. This explains that, due to your condition, you need toilet facilities urgently. It may be helpful to show this if there is a long queue for the toilet, or if you want to use a shop's facilities. See <u>Help and support</u> from Crohn's & Colitis UK for further details.

**Radar Key:** A Radar Key is a key for accessible public toilets. A Radar Key is available from Crohn's & Colitis UK if you become a member. You can also buy one from <u>Disability</u> <u>Rights UK</u>.. See <u>Help and support</u> from Crohn's & Colitis UK for further details.

**Travelling by car:** Many people who experience incontinence plan their journeys by toilet stops. This is sometimes called toilet mapping. There are many toilet map apps available that can help you plan your journey. Or you could use online resources such as the <u>Great</u> <u>British Toilet Map</u> to help you find the nearest public toilet when out and about.

**Travelling by public transport:** Using public transport can be a challenge if you need easy access to a toilet. For long-distance travel, most coaches now have an on-board toilet. And you can check the location of facilities at train stations in the UK via the <u>National</u> <u>Rail website</u>.

**Travelling by air:** If possible, request in advance an aisle seat near the toilet. Take a small supply of everything you need in your hand luggage. An '<u>**Emergency kit**</u>' can be useful, but check with the airline if they allow neutraliser spray on the plane.

**Staying away:** If you are going to stay away overnight you might like to think about bedding and laundry arrangements. You could take a towel or light-weight waterproof mattress protector to put under you in bed if bowel leakage at night might be a problem. You can buy disposable bed protection sheets online. Check laundry arrangements before you travel. A tube of detergent, a folding coat hanger and a portable washing line with pegs can be useful if you need to do your own washing.



### **Other organisations**

<u>Bladder and Bowel UK</u>: Provide information and advice on bladder and bowel health issues, continence promotion and options for managing incontinence, as well as signposting to local services. https://www.bbuk.org.uk/

<u>Continence Product Advisor</u>: Provide information and advice on continence products. www.continenceproductadvisor.org/

<u>Disability Rights UK</u>.: Radar keys can be bought from the online shop. https://shop.disabilityrightsuk.org/

<u>Great British Toilet Map</u>: An easy to navigate website that enables people to find their nearest publicly accessible toilet, no matter where they are in the UK. www.toiletmap.org.uk

### Help and support from Crohn's & Colitis UK

We're here for you whenever you need us. Our award-winning resources on Crohn's Disease, Ulcerative Colitis, and other forms of Inflammatory Bowel Disease have the information you need to help you manage your condition.

We have information on a wide range of topics, from individual medicines to coping with symptoms and concerns about relationships and employment. We'll help you find answers, access support, and take control.

All information is available on our website: crohnsandcolitis.org.uk/information

Our Helpline is a confidential service providing information and support to anyone affected by Crohn's or Colitis.

Our team can:

- Help you understand more about Crohn's and Colitis, diagnosis, and treatment options.
- Provide information to help you live well with your condition.



- Help you understand and access disability benefits.
- Be there to listen if you need someone to talk to.
- Help you to find support from others living with the condition.

Call us on 0300 222 5700 or email helpline@crohnsandcolitis.org.uk.

See our website for LiveChat: crohnsandcolitis.org.uk/livechat.

#### Crohn's & Colitis UK Forum

This closed-group community on Facebook is for everyone affected by Crohn's or Colitis. You can share your experiences and receive support from others at: facebook.com/groups/CCUKforum.

#### Help with toilet access when out

Members of Crohn's & Colitis UK get benefits including a Can't Wait Card and a RADAR key to unlock accessible toilets. This card shows that you have a medical condition, and will help when you need urgent access to the toilet when you are out. See <u>crohnsandcolitis.org.uk/membership</u> for more information, or call the Membership Team on 01727 734465.

Crohn's & Colitis UK information is research-based and produced with patients, medical advisers and other professionals. They are prepared as general information and are not intended to replace advice from your own doctor or other professional. We do not endorse any products mentioned.

### About Crohn's & Colitis UK

We are Crohn's & Colitis UK, a national charity fighting for improved lives today – and a world free from Crohn's and Colitis tomorrow. To improve diagnosis and treatment, and to fund research into a cure; to raise awareness and to give people hope, comfort and confidence to live freer, fuller lives. We're here for everyone affected by Crohn's and Colitis.



This information is available for free thanks to the generosity of our supporters and members. Find out how you can join the fight against Crohn's and Colitis: call **01727 734465** or visit <u>crohnsandcolitis.org.uk</u>.

### **About our information**

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We hope that you've found this information helpful. You can email the Knowledge and Information Team at <u>evidence@crohnsandcolitis.org.uk</u> if:

- You have any comments or suggestions for improvements.
- You would like more information about the research on which the information is based.
- You would like details of any conflicts of interest.

You can also write to us at Crohn's & Colitis UK, 1 Bishops Square, Hatfield, Herts, AL10 9NE or contact us through the Helpline: 0300 222 5700.

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