



MANAGING BOWEL INCONTINENCE AND IBD

INTRODUCTION

Bowel incontinence is the unintended passing of stools (faeces, poo), which can affect people with Crohn's Disease, Ulcerative Colitis and other forms of Inflammatory Bowel Disease (IBD). This information sheet explores the causes of incontinence and will help you find ways to manage it physically, practically and emotionally.

If you struggle with high output from your stoma, you may find looking at our **Living with a Stoma** sheet useful.

CONTENTS

WHAT IS INCONTINENCE?	1
HOW MANY PEOPLE WITH CROHN'S OR COLITIS ARE AFFECTED BY INCONTINENCE?	2
WHAT CAUSES INCONTINENCE?	2
IMPROVING INCONTINENCE	3
USING THE GASTRO-COLIC RESPONSE TO YOUR ADVANTAGE	4
MANAGING GAS	5
SKINCARE	5
GETTING RID OF SMELLS	5
PRODUCTS AND TIPS WHICH MIGHT HELP	5
GOING OUT?	6
GOING AWAY?	7
MANAGING STRESS AND ANXIETY	7
HELP AND SUPPORT FROM CROHN'S & COLITIS UK	8
OTHER ORGANISATIONS	9
PELVIC FLOOR EXERCISES	10

WHAT IS INCONTINENCE?

Bowel incontinence is the unintended passing of stools or poo.

There are two main forms of bowel incontinence:

- **Urge incontinence** - This happens when there is a very strong need to pass stools, but the person does not reach the toilet in time.
- **Passive incontinence** - This occurs 'silently' - that is, without the person being aware the stools have passed.

HOW MANY PEOPLE WITH CROHN'S OR COLITIS ARE AFFECTED BY INCONTINENCE?

As many as three in four people with Crohn's or Colitis have experienced incontinence. Often this is linked to flare-ups, but for about one in ten, incontinence occurs even when their disease isn't active. Incontinence, or the fear of experiencing incontinence, can make you worried about leaving home, which can seriously affect your work and social life.

.....

WHAT CAUSES INCONTINENCE?

The way the body manages bowel control is very complex involving nerves and muscles. In IBD, problems may arise due to the condition itself, or because of other factors, such as Irritable Bowel Syndrome (IBS) which can cause bowel control problems for people whether or not they have IBD.

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

- **An 'overactive' bowel or loose stools**
Crohn's and Colitis often causes diarrhoea, or loose stools. Some people have bowels which are a lot more active than others, or are easily upset.
- **Increased sensitivity**
Crohn's and Colitis cause the bowel to become inflamed, which makes it more sensitive. Inflammation in the rectum increases the sense of urgency, so it becomes more active, pushing stools out as soon as they arrive. If stools are loose, or overactivity in the bowel is causing the rectum to fill more often, this may be difficult to control.
- **Damage to the muscles**
Muscle control is crucial to bowel control. The muscles of the anus can be damaged by childbirth, or by an anal fistula, which is an abnormal channel connecting the anal canal or back passage to the surface of the skin near the anus. They can be damaged by surgery for a fistula or to form a pouch – see below: Surgery for Crohn's or Colitis. Anal muscles can also become weaker and thinner with age.
- **Damage to the nerves**
Nerves control both the feelings (sensations) from the bowel, and the ability to control a full rectum, for example by squeezing the external muscle of the anus to prevent the passage of stools. Nerves can be damaged from birth, or later in life. For some people, nerves can be damaged by a neurological problem (a problem with the nervous system, brain or spinal cord).
- **Surgery for Crohn's or Colitis**
Pouch surgery (operation to create an internal pouch after removal of the colon), removal of a length of the bowel, or surgery for an anal fistula or abscess can increase the likelihood of bowel incontinence.
- **Severe constipation**
Some people with Crohn's or Colitis experience constipation rather than diarrhoea. If the lower bowel becomes overloaded with hard stools, this irritates the bowel lining which then produces more mucus. If the rectum is full continuously, the muscles of the anus relax which means that the liquid mucus may bypass the hard stool and leak out. This can be mistaken for diarrhoea.

If you are not drinking enough fluids, this can contribute to constipation. You might find increasing the amount you drink will help to reduce it. The recommended fluid intake in countries with a climate like the UK is 6-8 average-sized glasses of water per day. See our information sheets on **Diarrhoea and Constipation** and **Dehydration** for more details.

- **Perianal fistulas**

These connect the anal canal (back passage) to the surface of the skin near the anus. They can sometimes leak blood or mucus, but they might leak faeces, which can lead to incontinence. See our leaflet **Living with a Fistula** for more information.

IMPROVING INCONTINENCE

There are several things you can do to help the difficult problem of an unpredictable or leaking bowel. Different things work for different people. See below for suggestions to help with the control of your bowel. Talking about incontinence can be difficult, but it's important to mention it to your IBD team. They can help you manage it, and look into any underlying causes.

- **Bowel retraining**

For people with urgency and frequency (needing to rush to the toilet very often), it can help to practise holding on and waiting once you feel the urge. This can feel nearly impossible at first. Even with practice, it may take some time to work. For some people it may not work at all. Your rectum and your sphincter muscles, along with your confidence, need developing to help you to try to retrain your bowel. See below for some suggestions how to do this.

- **Making sure the bowel is empty**

Sometimes when the rectum is inflamed it can be difficult to be sure you are empty when you have been to the toilet. This can be a particular problem for people with an ileo-anal pouch. Sometimes, sitting on the toilet with your feet up on a footstool and pushing from your abdominal muscles (rather than holding your breath and pushing) can help. There is more information about this in our **Diarrhoea and Constipation** sheet.

- **Pelvic floor exercises**

The pelvic floor muscles are located at the base of your pelvis (the frame of bones near the base of the spine which provides support for organs including your bowel, womb and bladder). The pelvic floor muscles run from your pubic bone at the front to the base of your spine at the back. You might already be familiar with exercises using these muscles. Some women use them to strengthen weakened muscles after childbirth and both men and women use pelvic floor exercises to help when their muscles have become weaker with age and they are experiencing urinary (wee) incontinence. Pelvic floor exercises can also help with managing bowel incontinence by strengthening the muscles around your anus. See Pelvic Floor Exercises on page 10 of this information sheet for more details about how to do these.

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. At first, you should set aside some time for these exercises to concentrate on getting them right. But quite soon they should become easy to do wherever you are. As your muscles strengthen, you should be able to hold each squeeze for longer and do more repeats. Some people also find that gentle exercise such as swimming and Pilates can help to strengthen the pelvic floor muscles.

- **Biofeedback therapy**

Biofeedback may be used with pelvic floor exercises to help retrain your bowel. This is a technique in which a small device is placed in your bottom before doing the exercises. The device provides information about how well the muscles are working while you're doing the exercises. The therapist uses this information to give you exercises that help to improve control and reduce symptoms such as incontinence. This therapy is not yet widely available, but you can ask your IBD team if they are able to provide this service, or if they can refer you to another hospital or centre where it is available.

- **Antidiarrhoeal drugs**

People with bowel incontinence who also have diarrhoea or loose stools often find that taking anti-diarrhoeal drugs to firm up the stools is helpful, as these can decrease incontinence and urgency. However, you should not take these if you are having a flare-up as it can lead to serious complications. Check with your doctor or IBD team before taking anti-diarrhoeals. See our information sheet **Other Treatments for IBD** for further details.

- **Food and drink**

Some people find altering what they eat helps to reduce their diarrhoea and risk of incontinence. For more information about this, see our leaflet **Diarrhoea and Constipation**. You might also find our **Food and IBD** booklet useful (see below).



USING THE GASTRO-COLIC RESPONSE TO YOUR ADVANTAGE

The gastro-colic response refers to the wave of pressure called 'peristalsis' that travels down the large intestine (colon and rectum) whenever you swallow food or drink. This pressure moves food towards the rectum. For some people with Crohn's or Colitis, this response can be very strong and result in a need to open their bowels during or immediately after eating. As a result, many people with Crohn's or Colitis avoid eating in the mornings when their bowels are most active, especially if they are about to leave the house. While this could reduce the need to use the toilet away from home, you'll be going through your day without enough energy and nutrients to stay healthy. Our **Food and IBD** booklet has more information and suggestions about healthy eating with Crohn's or Colitis.

Some people can manage their bowel by allowing sufficient time to eat, and then visiting the toilet several times to be sure that the bowel is completely empty before leaving the house. Rather than avoid the gastro-colic response, they use it to ensure their bowel is empty and reduce the likelihood of needing the toilet, or having a bowel accident, later in the day.



MANAGING GAS

Controlling gas (wind) is often the most difficult aspect of bowel control. Most of the suggestions outlined above apply to controlling gas as well as controlling stools, and the same exercises and routines can be helpful in managing gas. Many people find that diet has a big influence on how much gas their bowel produces, and how it smells. Foods that produce a lot of gas vary between individuals, so it is worth experimenting, but it is not possible to eliminate gas altogether.

If your bowel is inflamed, it may be hard to tell the difference between stools and gas. You may find that you have a lot of “false alarms” and run to the toilet when it was only gas, or think you are safe to pass gas but find that you have also passed some loose stools. Bear in mind that you will be a lot more aware of your body functions than the people around you. Most people pass gas 5-15 times each day, yet how often do you notice anyone else doing this? In reality, people are busy with their own lives and are unlikely to notice your accidental passing of gas. See our leaflet **Managing Bloating and Wind** for more information about managing gas.

SKINCARE

Bowel incontinence or frequent bowel motions can cause sore skin, which can be uncomfortable and distressing. You might find it helpful to wash around the anus after a bowel movement, and use moist toilet paper or toilet wipes instead of dry toilet paper. Barrier creams and wipes can be used to protect the skin from faeces, though you should check with your doctor or nurse before using these. For more tips on protecting your skin, see our information sheet on **Diarrhoea and Constipation**.

GETTING RID OF SMELLS

If you are concerned about smells, you could use a neutralising spray to eliminate odours. Brands available include Neutradol Spray and Fresh Drop Smell Stop, or, on prescription only, AuriCare Odour Eliminator. There are deodorants designed for people with a stoma which might also be useful.

PRODUCTS AND TIPS WHICH MIGHT HELP

There aren't many products designed specifically for faecal (poo) incontinence, but see below for some items available and tips which may help you.

- **Pads and underwear** – Many pads are designed for urinary (wee) incontinence so people often find them unnecessarily thick and bulky, and not the right shape or length. However, there are some faecal incontinence pads available online and from chemists which may be suitable. These pads can help to contain soiling and prevent the skin from getting sore.

For more severe or regular incontinence you can obtain larger pads or specially designed padded pants which will prevent leaks staining clothes. These may be available for free on the NHS from your District Nurse - contact your GP surgery for more information. Or you may be able to get some free samples from the manufacturer's website. If you are unable to get free supplies, there are many companies with a mail order service.

- **Anal plug** – This is inserted into the back passage, where it expands to prevent leakage. It can be kept in place for up to 12 hours, though many people find that it is uncomfortable or irritating. It must be taken out before a bowel movement, so it is not suitable if you have frequent movements. Speak to your IBD team if you are thinking of using an anal plug, as they are not suitable for everyone.
- **Continence Clinics** – For personal help and advice you might attend a continence clinic (which may also be known as a continence advisory service). You may be able to refer yourself or you may have to be referred by your doctor or IBD service.

Bladder and Bowel UK have more information on the products and services mentioned above - see **Other organisations** below. Stoma care companies also often have useful information.

.....

GOING OUT?

Having an 'accident' can be very embarrassing. Planning ahead will help to give you more confidence to be away from home.

- **Emergency kit** – Carry a supply of pads, pants, alcohol-free wet wipes, tissues, nappy disposal bags (to carry soiled pants home), a small mirror (useful to check that you are clean), a couple of clothes pegs (to keep your clothes out of the way if you need both hands to get clean), a neutraliser aerosol to disguise odour, and cream such as zinc and castor oil cream, if you are prone to sore skin. You may also wish to have a change of clothes both at work and in the boot of your car, just in case of any accidents.
- **Clothing** – Wear trousers or skirts that are easy to undo, perhaps with an elasticated waist or Velcro instead of buttons. Darker colours may disguise leaks more easily. Women may find it preferable to wear a skirt, which conceals accidents better, and to carry a spare pair of tights. The online Continence Product Advisor has more information on clothing and modifications which can help with managing incontinence. More details about this website can be found in **Other Organisations** at the end of this leaflet.
- **Can't Wait Card** – If you are a member of Crohn's & Colitis UK, you can carry your 'Can't Wait' Card which explains that due to your illness you need toilet facilities urgently. It may help to show this if there is a long queue for the toilet or if you want to use a shop's facilities. See **Help and support from Crohn's & Colitis UK** for further details.
- **Travelling by car** - Many people who experience incontinence plan their journeys by "toilet stops", sometimes referred to as toilet mapping. There are many toilet map apps available online which can help you plan your journey. Other online resources such as the Great British Toilet Map can also be useful in locating your nearest public toilet when out and about. See **Other organisations** for more information.

66

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, age 39
Diagnosed with Crohn's Disease in 2002

- **Travelling by public transport** - Using public transport can be a real challenge if you need ready 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 National Rail website: www.nationalrail.co.uk.
- **Radar Key** - You might find it helpful to buy a key for public toilets for people living with a disability from the Disability Rights UK Radar Shop (see **Other organisations**). The Radar Shop can also provide a list of all known publicly accessible toilets for a small additional cost. The Radar Key is also available from Crohn's & Colitis UK if you become a member. See **Help and support from Crohn's & Colitis UK** for more details.

GOING AWAY?

If you are going to stay away overnight you might also like to think about bedding, travel and laundry arrangements.

- **Bed protection** – 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.
- **Laundry** – 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.
- **Air travel** – If possible, request in advance an aisle seat near the toilet. Take a small supply of everything you need in your hand luggage. An 'Emergency kit' like that described earlier can be very useful, but you should check with the airline if neutraliser spray is allowed on the plane. For more information and tips see our leaflet **Travel and IBD**.

“

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, age 36

Diagnosed with Colitis in 2007

MANAGING STRESS AND ANXIETY

Many people with Crohn's or Colitis find that stress plays a role in their symptoms. Research also suggests that stress can trigger flare-ups or make symptoms worse. Almost everyone, regardless of whether they have Crohn's or Colitis or not, can experience 'butterflies' in the stomach and feel uncertainty in their bowels if they are facing a situation they feel nervous about.

If you are anxious about managing your symptoms at work, it might help to speak to your employer about your condition. We have two information sheets which give more details on this and how to handle Crohn's or Colitis at work: **Employment and IBD: a guide for employers** and **Employment and IBD: a guide for employees**.

It may be worth keeping a diary to see when your symptoms are worse, and whether this is connected to a stressful event. Identifying the effect of stress on your bowel, and developing ways to minimise that stress, can reduce the effect it has. You may be able to use relaxation and stress-relieving techniques, such as learning when to say “No” to additional work and family-related pressures, or making time to do something calming you enjoy.

MANAGING BOWEL INCONTINENCE AND IBD

Talking about how you are feeling can help. You might find it comforting to let your loved ones know what you're going through, and show them our information sheet on **Supporting Someone with IBD: A Guide For Friends and Family**. Talking through your concerns with a professional counsellor can also be of great benefit. Our information sheet **Counselling and IBD** has more details about how counselling could help you, and ways to find a counsellor.

Sometimes it can help to speak to someone who understands what it's like to have IBD. Our confidential listening service Crohn's & Colitis Support is run by volunteers who have personal experience of IBD and are trained in giving emotional support. See **Help and support from Crohn's & Colitis UK** below for details of how to get in touch.

You might also find it reassuring to speak to other people with IBD and share experiences through the Crohn's & Colitis UK Facebook Forum. See **Help and support from Crohn's & Colitis UK** for more details.

HELP AND SUPPORT FROM CROHN'S & COLITIS UK

We offer more than 50 publications on many aspects of Crohn's Disease, Ulcerative Colitis and other forms of Inflammatory Bowel Disease. You may be interested in our comprehensive booklets on each disease, as well as the following publications:

- **Managing Bloating and Wind**
- **Diarrhoea and Constipation**
- **Dehydration**
- **Fatigue and IBD**
- **Counselling for IBD**
- **Food and IBD**
- **Understanding IBD**
- **Other treatments for IBD**
- **Supporting someone with IBD: a guide for friends and family**

All publications are available to download from: **www.crohnsandcolitis.org.uk/publications**. Health professionals can order booklets in bulk by using our bulk ordering system.

If you would like a printed copy of a booklet or information sheet, please contact our Helpline - a confidential service providing information and support to anyone affected by Inflammatory Bowel Disease. Our team can:

- help you understand more about IBD, diagnosis and treatment options
- provide information to help you to live well with your condition
- help you understand and access disability benefits
- be there to listen if you need someone to talk to
- put you in touch with a trained support volunteer who has a personal experience of IBD

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

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

Crohn's & Colitis UK Forum

This closed-group community on Facebook is for everyone affected by IBD. You can share your experiences and receive support from others at: **www.facebook.com/groups/CCUKforum**

Help with toilet access when out and about

If you become a member of Crohn's & Colitis UK, you will get benefits including a Can't Wait Card and a Radar key to unlock disabled toilets.

This card shows that you have a medical condition, and combined with the Radar key will help when you need urgent access to the toilet when you are out and about. See our website for further information: www.crohnsandcolitis.org.uk/membership or call the membership team on: 01727 734465.

.....

OTHER ORGANISATIONS

Bladder and Bowel UK

Website: www.bbuk.org.uk
Email: bladderandboweluk@disabledliving.co.uk
Telephone: 0161 607 8219

Part of Disabled Living, who provide impartial information and advice about products, equipment (assistive technology) and services for disabled adults, children, older people, carers and the professionals who support them.

Continence Product Advisor

Website: www.continenceproductadvisor.org
A website providing evidence-based guidance on how to choose products for incontinence and how to use them correctly.

ERIC (The Children’s Bowel and Bladder Charity)

Website: www.eric.org.uk
Email: helpline@eric.org.uk
Helpline: 0845 370 8008*

*Calls to the Helpline cost 9.6p per minute plus service provider charge.
Provides expert support, information and understanding to children and teenagers and enable parents, carers and professionals to help them establish good bowel and bladder health.

BACP (British Association for Counselling and Psychotherapy)

Website: www.bacp.co.uk
Email: bacp@bacp.co.uk
Telephone: 01455 883300

Provides information about types of therapy, and how to find a safe and effective counsellor or psychotherapist.

Disability Rights UK

Website: www.disabilityrightsuk.org
General enquiries: 0330 995 0400
Email: enquiries@disabilityrightsuk.com

From this organisation, you can purchase Radar keys which allow access to specially adapted toilets.

Great British Toilet Map

An interactive map of Great Britain’s toilets.
www.toiletmap.org.uk

Irritable Bowel Syndrome Network (The IBS Network)

Website: www.theibsnetwork.org
Telephone: 0114 272 3253
Email: info@theibsnetwork.org

The IBS Network is an independent, self-help organisation for people with Irritable Bowel Syndrome. The helpline is staffed by specialist IBS nurses.

.....

OTHER INFORMATION

Dealing with incontinence is a challenge for the person with IBD, and their family. This resource may be helpful:

Managing Life With Incontinence by Gartley CB, Klein MR, Norton C, Saltmarche A. 2012; Wilmette, Ill: Simon Foundation

PELVIC FLOOR EXERCISES

How to do a pelvic floor exercise

- Sit or stand comfortably with your knees slightly apart.
- Now imagine that you are trying to stop yourself passing wind from the bowel. To do this, you must squeeze the muscle around the back passage.
- Try squeezing and lifting that muscle as tightly as you can, as if you are really worried that you are about to leak. You should be able to feel the muscle move. Your buttocks, abdomen and legs should not move much at all.
- You should be aware of the skin around the back passage tightening and being pulled up and away from your chair if you are sitting. Really try to feel this – you are now exercising your anal sphincter muscles. You should not need to hold your breath when you tighten the muscles.
- When you squeeze as tightly as you can, it is likely that you will not be able to hold it there for very long, and it will not get you safely to the toilet as the anal sphincter muscle will get tired very quickly. So now squeeze more gently (try to imagine squeezing half way to the maximum). Feel how much longer you can hold it than at the maximum squeeze.

How to do a “fast-twitch” exercise

“Fast-twitch” exercises are squeezing and relaxing as quickly as you can. These are for when you may need to activate the muscles very quickly (for example if you are going to pass wind).

How to practise your pelvic floor exercises

To work on the strength of your muscles:

- Sit, stand or lie with your knees slightly apart. Slowly tighten and pull up your anal muscles as tightly as you can. Hold tightened for at least 5 seconds, then relax for at least 10 seconds.
- Repeat at least 5 times.

Then, to work on the endurance (staying power) of your muscles:

- Pull the muscles up to about half of their maximum squeeze. See how long you can hold this for. Then relax for at least 10 seconds.
- Repeat at least 5 times.

How to continue with your pelvic floor exercises

Once you have mastered your pelvic floor exercises (see above):

- Pull up the muscles as quickly and tightly as you can and then relax and then pull up again. See how many times you can do this before you get tired.
- Try for at least 5 quick pull-ups.
- Do these exercises 5 as hard as you can, 5 as long as you can and as many quick pull-ups as you can - at least three times every day.

As the muscles get stronger, you will find that you can hold for longer than 5 seconds, and that you can do more pull ups each time without the muscle getting tired.



Crohn's & Colitis UK publications are research based and produced in consultation with patients, medical advisers and other health or associated professionals. They are prepared as general information on a subject and are not intended to replace specific advice from your own doctor or any other professional. Crohn's & Colitis UK does not endorse or recommend any products mentioned.

Crohn's & Colitis UK is an accredited member of the Information Standard scheme for Health and Social Care information producers. For more information see www.crohnsandcolitis.org.uk and the Information Standard website: www.england.nhs.uk/tis.

We hope that you have found this leaflet helpful and relevant. If you would like more information about the sources of evidence on which it is based, or details of any conflicts of interest, or if you have any comments or suggestions for improvements, please email the Publications Team at publications@crohnsandcolitis.org.uk. 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**.

Follow us

 /crohnsandcolitisuk

 @CrohnsColitisUK

 @crohnsandcolitisuk

ABOUT CROHN'S & COLITIS UK

We are a national charity established in 1979, fighting for improved lives today and a world free from Crohn's and Colitis tomorrow. We have 40,000 members and 50 Local Networks throughout the UK. Membership costs start from £15 per year with concessionary rates for anyone experiencing financial hardship or on a low income.

This publication is available free of charge, but we would not be able to do this without our supporters and members. Please consider making a donation or becoming a member of Crohn's & Colitis UK. To find out how call **01727 734465** or visit crohnsandcolitis.org.uk



© Crohn's and Colitis UK 2018
Managing Incontinence and IBD
Last review: October 2018
Next planned review: 2021

1 Bishops Square | Hatfield | Herts | AL10 9NE | 0300 222 5700 | helpline@crohnsandcolitis.org.uk | crohnsandcolitis.org.uk