



MANAGING BOWEL INCONTINENCE IN IBD

INTRODUCTION

The risk of bowel incontinence can be part of having IBD (Inflammatory Bowel Disease – the main forms of which are Crohn's Disease and Ulcerative Colitis.) Bowel incontinence means the unintended passing of stools (faeces, poo). This leaflet aims to introduce you to ways to manage the risk of incontinence physically, practically and emotionally.

WHAT IS BOWEL INCONTINENCE?

As mentioned above, bowel incontinence means the unintended passing of stools or poo.

There are two main forms of bowel incontinence. They are:

- **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 that stools have been passed.

HOW MANY PEOPLE ARE AFFECTED BY INCONTINENCE?

Probably as many as three in four people with IBD have had some experience of incontinence. Often, this is linked to flare-ups, but for about one in ten, incontinence occurs whether their disease is active or not. People who have suffered such incontinence can be very reluctant to leave their home, which can seriously affect work options and social activities. For others who might not have experienced actual incontinence, the fear that it could happen can cause similar limitations.

WHAT CAUSES BOWEL INCONTINENCE?

The way the body manages bowel control is very complex. Problems may arise due to IBD itself, or as a result of other factors that can cause bowel control problems for people whether or not they have IBD. The most common causes of bowel incontinence for people with IBD are:

- **An 'overactive' bowel or loose stools**
When IBD is active (and sometimes when it is not) you are likely to have diarrhoea, or loose stools. Some people have bowels that are a lot more active than others, or are sensitive and easily upset.

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- **Increased sensitivity**

Any part of the body that is inflamed is more sensitive and the bowel is no different. Inflammation in the rectum can increase the sense of urgency. As a result, the rectum becomes more active, pushing stools out as soon as they arrive. If stools are loose, or the activity in the bowel is causing the rectum to fill more often, this will be more 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 (abnormal channel connecting the back passage to the surface of the skin near the anus). The muscles can also be damaged by surgery for a fistula or to form a pouch – see below **Surgery for IBD**.

- **Damage to the nerves**

Nerves control both the feelings (sensations) from the bowel, and the ability to do something about a full rectum, such as keeping the external muscle of the anus closed. Nerves can be damaged from birth, or later in life.

- **Surgery for IBD**

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 for some people.

- **Severe constipation**

Some people with IBD 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. Drinking enough fluid can help relieve constipation. See our information sheet on **Diarrhoea and Constipation** for more details about this.

- **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.

MANAGING INCONTINENCE

There are no simple solutions to the difficult problem of an unpredictable or leaking bowel, but there are things you can try that may improve control for you. Different things work for different people. Some of the suggestions below may not be right for you, or you may have tried some already. But you may find that they help with the control of your bowel. Many people with IBD find it difficult to talk about their incontinence. But it is important to mention it to your IBD team so that they can check for any underlying causes and they can also help you to control and manage it.

- **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 very difficult, if not impossible, at first. Your rectum and your sphincter muscles, along with your confidence, need developing to help you overcome this problem. See **Pelvic floor exercises** below for some suggestions on how to do this.

- **Biofeedback therapy**

Biofeedback therapy for bowel incontinence is used as one way of retraining the bowel muscles to improve control and reduce symptoms such as incontinence. This therapy is not yet widely available. But it is worth speaking to your IBD team to see if they are able to offer it, or can refer you to another hospital or centre where it is available.

- **Making sure the bowel is empty**

Sometimes when the rectum is inflamed you can get mixed messages and it can be difficult to feel if you are empty or not when you have been to the toilet. This can be a particular problem for people with an internal 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.

- **Pelvic floor exercises**

The pelvic floor muscles are located between your legs, and run from your pubic bone at the front to the base of your spine at the back. You may already be aware of pelvic floor exercises, as some women use them to strengthen weakened muscles after childbirth. And both men and women can use these exercises to help when their muscles have become weaker with age and they may be experiencing urinary (wee) incontinence. But pelvic floor exercises can also help with managing bowel incontinence as they strengthen the muscles around your anus. (See the **Pelvic Floor Exercises** boxes at the end of this information sheet for more details about how to do these.)

It is important to learn to do the exercises in the right way, and to check from time to time that you are still doing them correctly. At first, it is probably a good idea to 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. Gradually doing a little more and feeling that you have worked hard should be your objective. Some people also find that gentle exercise such as swimming and pilates can help to strengthen pelvic floor muscles.

- **Antidiarrhoeal drugs**

People with bowel incontinence who also have diarrhoea or loose stools often find that taking antidiarrhoeal drugs to firm up the stools is helpful, as these can decrease incontinence and urgency. However, the patient information leaflets that come with all antidiarrhoeals advise against taking them if you have IBD, particularly if you are having a flare-up of UC. This is because there are risks of side effects, including toxic megacolon (when digestive gases get trapped in the colon, making it swell up) associated with taking these drugs. So, whichever condition you have, do not take any antidiarrhoeal medicines without first checking with your doctor or IBD team. See our information sheet **Diarrhoea and Constipation** 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 squeeze (called ‘peristalsis’) which travels down through the entire gut, whenever you swallow food or drink. This squeeze moves food along through the bowel. For some people with IBD, this response can be very strong and result in an almost immediate need to open their bowels. As a result, many people with IBD avoid eating especially if they are about to leave the house. This appears to make sense, since it reduces the likelihood of needing access to a toilet away from home. But it also means that many are going through their working day without a sufficient energy and nutrient intake to keep healthy. Our **Food and IBD** booklet has more information and suggestions about healthy eating with IBD.

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 the bowel is empty and reduce the likelihood of needing the toilet, or having a bowel accident, later in the day.

MANAGING GAS

Controlling gas 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 also be helpful in managing gas. Many people find that diet has a big influence on how much gas your bowel produces and how it smells. Gassy foods vary between individuals, so it is worth experimenting yourself, but it will be impossible 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. It is worth mentioning that you will be a lot more aware of your body functions than people are around you. Most people pass gas 10-20 times each day, yet how often do you notice anyone else doing this? In reality, most people are tied up in their own lives and are unlikely to notice your accidental passing of gas. See our leaflet **Bloating and Wind** for more information about managing gas.

GETTING RID OF SMELLS

If you are concerned about smells, you may wish to use a neutralising spray, as this helps to eliminate odours rather than just mask them. Brands available include Neutradol Spray and Fresh Drop Smell Stop, or, on prescription only, AuriCare Odour Eliminator. There are deodorants which are designed for people with a stoma which may also be suitable.

PRODUCTS AND TIPS WHICH MIGHT HELP

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

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I use pull on incontinence pants for added security on long journeys. They're not too bulky and have a snug fit. I order free samples to try from the website before I buy.

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Denise, age 51

Diagnosed with Crohn's Disease in 2002

- **Pads and pants** – 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 free of charge on the NHS from your District Nurse - contact your GP's surgery for more information. Or you may at least 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 has to 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** – If you would like personal help and advice you might like to consider attending a continence clinic. You may be able to refer yourself or you may have to be referred by your doctor or IBD service.

For more information on the products and services mentioned above, contact the Bladder and Bowel Foundation (B&BF) or PromoCon. (See **Other organisations**). Stoma care companies also often have useful information.

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GOING OUT?

Having an 'accident' can be very embarrassing. Planning ahead should help give you the confidence to be away from home and you may find the following tips useful.

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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.

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Gillian, age 39

Diagnosed with Crohn's Disease in 2002

- **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. Women may find it preferable to wear a skirt, which conceals accidents more easily, and to carry a spare pair of tights. The Disabled Living Foundation has a factsheet on 'Clothing for Continence and Incontinence'.

- **Can't Wait card** – If you are a member of Crohn's and 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 and Colitis UK** for further details.

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- **Travelling by car** - Many people who experience incontinence plan their journeys by “toilet stops” (sometimes referred to as toilet mapping). This helps to alleviate some of the anxiety but if your bowel is unpredictable, incontinence can still occur. There are many toilet map apps available online which may help with planning your journey. Online resources such as the Great British Toilet Map can also be useful in locating your nearest public toilet on your journey. See **Other organisations** for more details.
- **Travelling by public transport** - Using public transport can be a real challenge for those who need ready access to a toilet. For long-distance travel, most coaches now have an on-board toilet, and you can check location of facilities for train stations in the UK via the National Rail website: www.nationalrail.co.uk.
- **Radar Key** - You may find it helpful to obtain a key for public toilets for disabled people from the Disability Rights UK Radar Shop (see **Other organisations**.) The Radar Shop can also provide a location guide to approximately 9,000 toilets throughout the UK. You may also be able to purchase a Radar key from your local council.

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 mattress protector to put under you in bed. There are also some companies online who offer disposable bed protection sheets.
- **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 an aisle seat near the toilet in advance. Take a small supply of everything you need in your hand luggage. An ‘Emergency kit’ like that described earlier could be very useful here. However, you may need to check with the airline that the neutraliser spray is allowable. If you are taking stoma bags make sure these are the ‘pre-cut’ versions as scissors may not be allowed on planes. For more information and tips, see our leaflet **Travel and IBD**.

SKIN CARE

Anyone who has bowel incontinence or frequent bowel motions may get sore skin from time to time, which can be both uncomfortable and distressing. For more information on how to treat sore skin, see our leaflet **Diarrhoea and Constipation**.

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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 IBD feel that stress plays a role in their symptoms. Research also suggests that stress may trigger flare-ups or make symptoms worse. Almost everyone, regardless of whether they have IBD or not, can experience ‘butterflies’ in the stomach and feel the 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 IBD 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 if this is connected to a stressful event. You may find that by identifying the effect of stress on your bowel, and developing ways to minimise that stress, that you are able to reduce the effect it has. You may be able to do your own relaxation and stress-relieving techniques, such as learning when to say “No” to additional work and family-related pressures, or deliberately doing something calming you enjoy.

Talking about how you are feeling can help. You may wish to talk to a professional counsellor (see our information sheet **Counselling and IBD**). Or you may want to speak to someone who understands what it’s like to have IBD. Our confidential listening service, Crohn’s and Colitis Support, is run by volunteers who have experience of IBD and are trained in giving emotional support (see **Help and support from Crohn’s and Colitis UK**).

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

HELP AND SUPPORT FROM CROHN’S AND COLITIS UK

All our information sheets and booklets are available to download from our website: www.crohnsandcolitis.org.uk. If you would like a printed copy, please contact our Information Line – details below.

Crohn’s and Colitis UK Information Line: 01727 734470, open Monday to Friday, 9 am to 5 pm, except Thursday open 9 am to 1 pm, and excluding English bank holidays. An answer phone and call back service operates outside these hours. You can also contact the service by email info@crohnsandcolitis.org.uk or letter (addressed to our St Albans office). Trained Information Officers provide callers with clear and balanced information on a wide range of issues relating to IBD.

Crohn’s and Colitis Support: 0121 737 9931: Open Monday to Friday, 1 pm to 3.30 pm and 6.30 pm to 9 pm, excluding English bank holidays. This is a confidential, supportive listening service, which is provided by trained volunteers and available to anyone affected by IBD. These volunteers are skilled in providing emotional support to anyone who needs a safe place to talk about living with IBD.

Crohn’s and 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

Can’t Wait Card

If you become a member of Crohn’s and Colitis UK, you will get benefits including a Can’t Wait card. This card shows that you have a medical condition and you need access to the toilet quickly. See the Crohn’s and Colitis UK website to join: www.crohnsandcolitis.org.uk. Or call the membership team on 01727 734465.

OTHER ORGANISATIONS

The Bladder and Bowel Foundation (B&BF)

SATRA Innovation Park, Rockingham Road, Kettering, Northants, NN16 9JH
Helpline: 0845 345 0165 (Caller to leave name and contact number in answerphone message and B&BF will return call. Caller will incur connection charge and minimum one minute charge to call this number.)
General Enquiries: 01536 533255
Email: info@bladderandbowelfoundation.org
Website: www.bladderandbowelfoundation.org
B&BF provides information and support for people with bladder and bowel problems.

The Disabled Living Foundation

380-384 Harrow Road, London W9 2HU
Helpline: 0300 999 0004
Email: helpline@dlf.org.uk
Website: www.dlf.org.uk
Provides information on equipment to help manage incontinence, including a fact sheet on 'Clothing for Continence and Incontinence'.

Disability Rights UK

12 City Forum, 250 City Road, London, EC1V 8AF
Telephone: 0207 250 8191
Website: www.disabilityrightsuk.org
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.
Website: greatbritishpublictoiletmap.rca.ac.uk

Irritable Bowel Syndrome Network (The IBS Network)

Unit 1.12 SOAR Works, 14 Knutton Road, Sheffield, S5 9NU
Telephone: 0114 272 3253
Email: info@theibsnetwork.org
Website: www.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.

PromoCon

Redbank House, St Chads Street, Cheetham, Manchester M8 8QA
Telephone: 0161 834 2001
Email: promocon@disabledliving.co.uk
Website: www.promocon.co.uk
Product information and advice for all people with incontinence problems.

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

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PELVIC FLOOR EXERCISES

How to do a pelvic floor exercise

- Sit 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. 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, try:

- Sitting, standing or lying 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.
- Repeating at least 5 times.

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

- Pulling 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.
- Repeating at least 5 times.

How to continue with your pelvic floor exercises

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

- Pulling up the muscles as quickly and tightly as you can and then relaxing and then pulling up again. See how many times you can do this before you get tired.
- Try for at least 5 quick pull-ups.
- Doing 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.

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ABOUT CROHN'S & COLITIS UK

We are a **national** charity established in 1979. Our aim is to improve life for anyone affected by Inflammatory Bowel Diseases. We have over 28,000 members and 50 local groups 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 or members. Please consider making a donation or becoming a member of Crohn's and Colitis UK. To find out how call **01727 734465** or visit www.crohnsandcolitis.org.uk

