

# Controlling your IBD

## Introduction

Living with IBD can be a challenge, but one which, with support, can be met. You may experience pain, unpleasant and stressful symptoms (such as an urgent need to go to the toilet), and/or incontinence, as well as fatigue. You will also have to pay attention to your diet and nutrition. However, it is important to realise that you are not alone; there are many, many people who have learned to manage their IBD on a daily basis.

This part of the website will provide you with useful strategies and solutions to enable you to face the future with optimism, to empower you to lead as normal a life as possible, and help you manage your IBD day by day.

## Urgency and Incontinence

### Top tips

Incontinence can appear in patients with severe IBD or after certain surgical procedures, and it can be socially isolating; however, there are strategies you can employ, and people who can help you, in order to manage the condition.

Build up your confidence before travelling by:

- doing research to locate toilets and plan ahead
- using your IBD organisation for help and advice
- use 'Can't wait Cards'
- keeping a change pack with you for emergencies

Be sure to check with your healthcare practitioner before taking any over-the-counter medicines.

Discuss the possible causes of your urgency or incontinence with your healthcare practitioner; keeping a record of events that you can discuss with your physician may help. The date, nature and severity of event, potential triggers and treatment action taken could be written in the record of events. If desired, a typical record sheet can be downloaded from [here](#).

### What is faecal incontinence and faecal urgency?

Faecal incontinence is the inability to control the passage of wind or stools (faeces) through the anus and can have a devastating effect on quality of life and psychological well-being. For some people faecal incontinence is limited to a slight occasional soiling of underwear, but for others, it can involve a considerable loss of bowel control.

Faecal urgency is the inability to wait or 'hang on' to go to the toilet to use the bowels. A sufferer has to get to the toilet as soon as they feel an urge to go. Accidents may not always happen, but faecal urgency is disabling.

Both conditions can occur in IBD and will most probably require personal management strategies, together with a wider support network (for example, from your partner and family). Help, support and advice are also available from your healthcare practitioner, and from your local IBD organisation.

### What can I do about my incontinence?

First of all, you are not alone; incontinence is experienced by more people than you think. However, if you do suffer from the condition in any way, you will probably realise that it can have important psychological implications. From the time we are toilet trained, we are expected to be able to handle going to the toilet. The following advice should help you to manage incontinence.

**Seek support:** although it is an embarrassing topic, it is important to learn to accept your incontinence - it is not your fault, it is a consequence of your disease. Try to discuss this with your healthcare professional, within your support group and/or with your family. Incontinence can be socially isolating as well as debilitating, so having a support network of people who know you, and understand the problems you face, is very important.

**Try to identify a cause:** you should also discuss the possible causes of your incontinence and urgency with your healthcare practitioner, as there may be treatment available depending on your personal circumstances. For example, is your problem caused by active disease? Is it a muscle tone or transit issue? Could it be due to pouchitis (Ileo-anal pouches are constructed for people who have had their large intestine surgically removed due to disease or injury; pouchitis is inflammation of this ileal pouch)? Or is it a consequence of an active infection (particularly if the incontinence is new and of sudden onset)? Finally, IBD can sometimes cause scarring that makes the walls of the rectum less elastic. Because the rectum can no longer stretch as much to hold stools, faecal incontinence results. IBD can also irritate rectal walls, making them unable to contain stools.

**Plan ahead:** on the practical side, it is very important that you do not feel house-bound because of faecal incontinence and urgency. It can be embarrassing and isolating, but if you plan your day or your journey (making this part of a personal daily routine), this will empower you. Give yourself confidence, and a feeling of control, by doing research and planning ahead before visiting new places. Try and find out the location of toilets beforehand. Contact your national IBD organisation for help. Each country has its own support schemes e.g. RADAR keys in the UK which allow people with IBD to use disabled facilities, TTT (Toilet Tom Tom) in Denmark. 'Can't Wait Cards' are also available in most countries: check the information about these on the [EFFCA](#) web-site. Smart phones which allow internet access can also help when on the move.

**Carry a change pack:** if you are experiencing urgency and incontinence it can be helpful to carry around some or all of the following: wet wipes, toilet paper, change of underwear, panty pads/liners, air freshener, disposable bags and tissues.