

# Controlling your IBD

## Managing life's ups and downs

### Top tips

- It can take time to adjust to living with IBD
- IBD may be part of your life, but it should not define who you are
- Living with IBD means balancing your disease with your life; there will be times when your health has to be prioritised over other activities
- It is important that you take responsibility for managing your disease, so that you are in a stronger position to deal with the other uncertainties that life brings to us all
- Learn to trust others and be clear about your needs and priorities
- It can take time to identify the most appropriate medication for you
- Remember to continue to take your medication during flares and through remissions

Chronic illness has a huge effect on all aspects of life. As well as having to deal with physical changes associated with the disease, you will also need to manage the psychological changes that occur. We are all different, and everyone has their own way of managing the uncertainty that comes with change.

In this section we will discuss the uncertainties that are associated with the changes you are likely to experience due to IBD, as well as changes due to life experiences.

### Changes due to IBD

Your disease will constantly change and progress. From diagnosis, to the occurrence of disease remission and flares, through to changes brought about by your medication, there are many different phases of your IBD. Some of these phases will be easier to manage than others.

**Diagnosis:** this is the first major change you will be confronted with. Your first reaction may be one of shock, because you have an illness that could affect you for the rest of your life. However, you may also be relieved that the cause of the unpleasant symptoms you have been experiencing has finally been identified and can now be treated. Accepting the long term nature of the disease is often difficult – but it is an important step. It is also important that you try to lead as normal a life as possible and not allow the disease to control you.

**Flares:** IBD is characterised by intermittent periods of active disease (flare/flare-up) followed by little or no disease activity (remission). The duration and severity of the active periods vary widely from person to person. The aim of treating IBD is to stop the flare-ups, and ensure the disease is back under control, hopefully into remission.

A flare will probably not resolve by itself, and specific treatment will be needed. Most people with IBD take a maintenance drug to help keep their symptoms controlled, and so these maintenance drugs will be continued during a flare-up. Other medications, diet modification, or other supportive treatments may be prescribed to bring the disease back under control.

The time between flares may be anywhere from weeks to years, and varies widely between patients – indeed, some individuals with IBD have never experienced a flare-up. There are thought to be many causes of flares, although there is not a great deal of clear evidence about each. For most people with IBD, the only way to discover what has caused their flare is through trial and error, such as by examining their food intake and their general activities. However, some common causes are recognised: foods (e.g. nuts, fruit and fried food can exacerbate symptoms relating to strictures in people with Crohn's disease); seasonal changes (particularly the spring and autumn) and smoking (Crohn's disease). [NB. With ulcerative colitis, there is some evidence that nicotine patches may suppress flares; however, smoking is **not** recommended as the dangers associated with smoking are far greater than any potential moderation of symptoms].

If you experience a flare-up you should continue with your medication, consult your healthcare practitioner, and follow whatever advice they may give you – which will be dependent on your personal circumstances.

Sometimes you may be doing all that has been asked of you, and you have committed fully to managing your disease – yet despite this you still get a flare. This is frustrating, upsetting and wearisome...but is not your fault. Unfortunately, it is the nature of IBD – flares come and go, sometimes with no obvious cause. There are some things which you can control, and there are other things you cannot. Do not worry about the things you cannot control but accept them, and focus on what you can positively control. Remember, you are not alone; persevere with your management strategies and do not lose heart.

Remission is when your IBD becomes inactive for a period of time. Patients and physicians have different views of the meaning of 'remission', in practical terms. Whereas 'clinical remission' (the absence of rectal bleeding, and normal stool frequency) is what the clinician will use in clinical practice, it is 'steroid-free remission' that often matters more to patients.

It is important that you still continue to take your medication during periods of remission, even if the medication has side-effects. Some medicines are designed to prevent the return of the inflammation, and if you stop taking them, there may be an increased chance of a relapse. It can be a problem remembering to take your medicine, especially when you are feeling well, so try to make taking it a part of your daily routine; for example at mealtimes or when brushing your teeth. If you start to suffer from any side-effects, talk to your healthcare practitioner, who can review or change your medication accordingly.

**Changes due to surgery:** sometimes surgery is the best way to treat severe IBD and can give enormous relief to the person suffering from IBD. The type of surgery largely depends on whether you have ulcerative colitis or Crohn's disease, and which part of the body is affected, as well as the severity of the disease. Surgery for ulcerative colitis usually involves partial or total removal of the large bowel (and is considered a cure for the disease), while a high proportion of patients with Crohn's disease will experience long periods of remission after surgery, depending on the location of the disease, and hence the type of surgery required.

Each area of the intestine has a specific function in the absorption of nutrients. If parts of the intestine are removed by surgery, then the absorption of some nutrients may be reduced or prevented. How this will affect you personally, and what life-style changes you may need to initiate and manage, will need to be discussed with your healthcare practitioner. It is normal to feel anxious about surgical procedures, and so it can also be very useful to talk to others who have experienced surgery.

**Surgical intervention is usually applicable only in cases of severe disease, so these changes are unlikely to affect you in mild disease**

**Changes due to medication:** when you first start to receive medication for your IBD, it may take a little while to find the optimum combination of medicines that suit you. This is perfectly normal, so do not be concerned if you find your medications are changed in this early period, until your doctor identifies what works best for you.

Many of the medicines used to treat IBD can have side-effects which may cause changes to your body. Such side-effects are very well recognised, predictable and most are relatively minor. However, if any begin to cause you concern, or reduce your quality of life, you should discuss them with your healthcare practitioner.

If you do experience any side-effects, and even if you do not, it is important that you continue to take your medications. Do not suddenly stop taking them (some drugs, such as steroids, require that you reduce the dose gradually) or alter the dose yourself, without consulting your doctor.

If you are taking certain drugs, such as steroids and immunosuppressants, you may be more vulnerable to developing infections. While it may be difficult, try to avoid people with coughs, colds, 'flu etc. Many healthcare professionals strongly recommend that individuals with IBD have an annual

influenza ('flu) vaccine and update vaccines before starting immunosuppressants as a precaution (although [immunisation guidelines](#) for people with IBD do not differ from the general population, with the exception of live agent vaccines). For women on immunosuppressants regular cervical screening is recommended, and if considering starting a family, any medication should be discussed with your healthcare physician.

## Changes in everyday life

Everyday life is all about transition. There are times in our lives when things are relatively stable, such as when we are living at home with our parents. Then, our life becomes more uncertain when we leave home, move in with friends or partners, or maybe even relocate. There are also times when we are developing stronger connections with others, such as when we find a partner, get married, and have children. As we get older we become more focused upon work and providing for the family, until such time as we can look forward to our retirement. So, life goes through different stages, and each of these can present us with challenges as well as rewards.

Having to manage IBD on top of these life challenges can be particularly stressful, especially when your disease is not stable. It can feel like you are living your life under a shadow; however, there are certain strategies you can employ to help.

**Prioritising your health:** there will be times when your health will have to take priority over other things such as hobbies, holidays, your social life or work. It can be frustrating when this happens, as it may be difficult to make long-term plans. However, things do change – difficult experiences do pass. Sometimes you will need to prioritise your health; at other times you will prioritise other important things in your life.

**Reducing the feeling of isolation:** you may be the only person in your family or social circle with IBD, and if this is the case it can feel very isolating. But remember that everyone experiences bowel problems at some point. Others may not understand what it is like to live with IBD, 24 hours a day, but they will appreciate some of the symptoms you experience. Making contact with others with IBD who understand what it is like (as they live with IBD too) can be a very positive experience. It is often reassuring to know that there are others who have the same condition as you.

**Developing trust in others:** many people with IBD are used to managing things on their own, or feel 'safe' only with family members or close friends. Not everyone needs to know about your IBD. However, there are times when it might be helpful to share information about your disease. Sharing this knowledge can reduce that worry about others finding out. If you are in work, it can also make it easier if your employer knows, so that if you need to take "time out" they are aware of the underlying reasons. You will find that most people, particularly those closest to you, are understanding and want to help out in any way they can. Sometimes people do not know what they can do to help, so it can be useful if you are clear about what you need.

**Self management** is a term used to describe how people take responsibility for their own health. Those who feel responsible for managing their health often cope better than those who leave the responsibility completely to their health professionals. You can learn to manage your own disease by:

- Taking an active role in discussions and decisions
- Monitoring changes and triggers (use the forms provided in this module or develop your own)
- Solving problems as they occur
- Prioritising the symptoms that you wish to address
- Trying to keep a positive focus
- Communicating clearly with your health care providers
- All of these things will help you feel more in control of your disease, your health, and your life.