Guide to Inflammatory Bowel Disease (IBD)

Know your gut. Live your life.

This booklet was created in partnership with the Department of Colorectal Disease, St. Vincent’s University Hospital, Dublin 4
“People with IBD suffer more severe conditions and are at risk of becoming nutrient deficient because of the intestine’s inability to absorb nutrients.”
What is IBD?

Inflammatory Bowel Disease (IBD) is a name for a group of disorders which cause inflammation of the intestine. It includes both Crohn’s disease and Ulcerative Colitis (UC) which are very similar but affect different parts of the digestive tract. UC affects the inner lining of the large intestine while Crohn’s disease can affect any part of the digestive tract from the mouth to the anus.

What is the difference between IBD and IBS?

IBD is not the same as Irritable Bowel Syndrome (IBS). Though some of the symptoms of IBD and IBS are similar, the two conditions are not the same as IBS does not cause inflammation of the gut. People with IBD suffer more severe conditions and are at risk of becoming nutrient deficient because of the intestine’s inability to absorb nutrients.

IBS stands for Irritable Bowel Syndrome, and IBD stand for Inflammatory Bowel Disease. One of the biggest distinctions is that IBS is a syndrome (a group of symptoms), whereas IBD is a disease. In simpler terms, IBD is where the immune system attacks the intestinal tissue whereby a patient’s intestines can become chronically inflamed and damaged.

As symptoms of IBD and IBS can be very similar, it can lead to confusion and oftentimes misdiagnosis. The GI tract looks normal in those who suffer from IBS, but often does not function normally. IBS patients can often experience contractions in the colon or rectum but inflammation in their intestines will not occur; nor is permanent intestinal damage caused.

Both conditions are idiopathic meaning the cause or onset is unknown. Not knowing the cause makes them difficult to treat, but managing your diet, medication and seeking the opinion of a GP or gastroenterologist will help you more accurately diagnose your condition.
How common is IBD?

Remember, you are not alone. An estimated 15,000 people in Ireland have IBD. IBD can be diagnosed at any age but people often find out they have the condition when they are between the ages of 15 and 30.

IBD occurs in people all around the world, but it tends to be most common in Europe where over 2 million people have the disease. It affects men and women equally.

The incidence and prevalence rates of Ulcerative Colitis and Crohn’s disease are beginning to stabilize in high-incidence areas such as northern Europe and North America, however, they continue to rise in low-incidence areas such as southern Europe, Asia, and much of the developing world. Prevalence relates to the numbers of people living with a disease at a given time, whereas incidence relates to the number of new cases diagnosed during a given time period.

What causes IBD?

The cause of IBD is generally unknown. Experts think that it is abnormal activity of a person’s immune system. Normally, the immune system protects the body from infections caused by bacteria or viruses and once the infection has been cleared, the immune system “shuts off”. However, in people with IBD, the immune system overreacts to normal bacteria and once it starts working the immune system fails to ‘shut off’ causing inflammation, which damages the digestive tract.

Other factors include genes, as IBD runs in families and suggests that genes play a role in causing IBD. Stress and eating certain foods can also contribute to making symptoms worse but do not cause IBD.
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What are the symptoms associated with IBD?

To help you start the discussion with your doctor, it may be helpful to take the questionnaire below to familiarise yourself with the common symptoms of IBD. Sometimes it can be difficult to talk about the symptoms of IBD. However, don’t let your embarrassment get in the way of getting help. As soon as your doctor knows about the way you are feeling, they can start to work with you to find the best treatment options for you.

“As soon as your doctor knows about the way you are feeling, they can start to work with you to find the best treatment options for you.”
Symptoms I am experiencing
(tick all that applies):

1. Do you suffer from extreme fatigue and tiredness?
   Yes [ ] No [ ]

2. Do you regularly experience fevers?
   Yes [ ] No [ ]
   (If yes, how often – estimate per week?)

3. As far as you are aware, have you recently experienced any weight loss?
   Yes [ ] No [ ]

4. Do you suffer from tummy pain after eating?
   Yes [ ] No [ ]

5. Do you suffer from nausea/vomiting after eating?
   Yes [ ] No [ ]

6. Have you noticed a change in your bowel habits?
   Yes [ ] No [ ]

7. Do you suffer from any constipation?
   Yes [ ] No [ ]
   (If yes, how often – estimate per week?)

8. Do you suffer from urgent diarrhoea?
   Yes [ ] No [ ]
   (If yes, how often – estimate per week?)

9. Do you, or have you previously experienced any rectal bleeding?
   Yes [ ] No [ ]
How is IBD diagnosed?

If you think you have Inflammatory Bowel Disease (IBD), talk to your doctor. Your diagnosis will be made using your health history, physical examination and various tests, in order to determine if you have IBD and if so, which type.

They might test a sample of your stool to see if it has any blood or germs in it. A colonoscopy or a sigmoidoscopy might also be performed to determine IBD as both procedures allow the doctor to see any inflammation in the intestine. For both procedures a long, thin tube with a lighted camera inside the tip is inserted into the anus so that your doctor can see the intestine on a large screen.

X-rays with barium: in this procedure, a thick, chalky liquid called barium is used to coat the lining of the digestive tract. The barium can be drunk or given as an enema. X rays are then taken and the areas coated with barium should show up white on x-ray film.

You may be asked to swallow a small, pill-shaped capsule camera called a capsule endoscopy. This travels through your digestive system, recording a video of the small intestine that your healthcare professional can review.

Diagnosis can take a while

Your doctor may not be able to diagnose you with IBD immediately. This is because the symptoms of IBD are different for every person and can sometimes mirror the symptoms of other health problems.
“Your doctor may not be able to diagnose you with IBD immediately. This is because the symptoms of IBD are different for every person and can sometimes mirror the symptoms of other health problems.”
How is IBD treated?

You may hear the words ‘remission’ and ‘flare’ used when describing symptoms associated with IBD. When symptoms are mild or patients are not having symptoms they are said to be in ‘remission’. When patients start experiencing symptoms again or they are particularly bad, it is called a ‘flare’.

Other symptoms which are not related to the bowel or digestive tract are referred to as extra intestinal manifestations and can include:

- Arthritis and joint pain
- Weak bones and bone breaks
- Eye redness / inflammation or discoloration of eye
- Liver inflammation
- Gallstones or kidney stones
- Delayed puberty and growth problems in children
- In rare cases, lung problems

One common problem that occurs because of loss of blood from the digestive tract is anemia. Anemia means that the amount of healthy red blood cells, which carry the oxygen to the organs, are below normal and often results in making the patient very tired.

Poor absorption of nutrients is often the cause of some of the health problems mentioned, others are due to inflammation in parts of the body other than the digestive tract. Some problems can get better when the patients’ IBD is treated, however others must be treated separately.
How is IBD treated?
There is no permanent cure for IBD but there are lots of treatment options available which can stem the ‘flares’ and control the disease so that your IBD does not need to take over your life.

- Once you have been diagnosed with IBD, the treatment your doctor decides is best for you will depend on a few different factors such as what part of your digestive tract is affected, how severe the disease is and how you are coping with your symptoms.

- The primary purpose of your treatment will be to stop you experiencing symptoms now and in the future and to get you back to the quality of life that you are used to.

- If you have mild to moderate Crohn’s disease, your doctor will likely try to treat with medicine first and that surgery will only be used after all other options have been exhausted.

IBD medication

- The medicines that are given to treat IBD will help to reduce the inflammation in your digestive tract and also help control your symptoms.

- Don’t forget that just as IBD affects every person differently, so do the medicines - so what works for one patient might not work for another. You might have to try a few different medications before you hit on the one that’s right for you.

- Keeping track of how each medication works for you and if it has any side effects as this can help your doctor decide on the best treatment.

- There are lots of different types of medicines that are given to people with IBD. These include aminosalicylates, corticosteroids, immunomodulators, biologics and antibiotics. Each work in a different way, are taken in a different way and have different side effects.

- Treatments for diarrhoea and pain are available without a prescription. However, talk to your doctor before you take any of these as they may interfere with your other medications or mean that you need a different type of treatment to cope with your symptoms.
## What treatments are available?

This table should give you an idea of what treatments are available so you can speak to your doctor to find the most suitable one for you.

<table>
<thead>
<tr>
<th>Treatment</th>
<th>Types</th>
<th>When are they used?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Aminosalicylates</td>
<td>Mesalazine, Olsalazine, Balsalazide, Sulfasalazine</td>
<td>Mild to moderate flare-ups</td>
</tr>
<tr>
<td>Steroids</td>
<td>Budesonide Prednisolone Hydrocortisone Methylprednisolone Prednisone</td>
<td>Moderate to severe flare ups, or if you don’t respond to aminosalicylates not recommended for long term use.</td>
</tr>
<tr>
<td>Immunosuppressants</td>
<td>Azathioprine Mercaptopurine Methotrexate</td>
<td>Moderate to severe flare ups. Usually used for maintenance therapy after steroids have been introduced and for symptom control after steroids alone have failed to control flares. Slow acting, so steroids may be used in conjunction in the beginning</td>
</tr>
<tr>
<td>Biologics</td>
<td>Anti - TNF</td>
<td>Moderate to severe flare ups. When the treatments listed above don’t provide enough control, or people can’t tolerate their side effects</td>
</tr>
<tr>
<td>Surgical option</td>
<td>Colectomy</td>
<td>Some people may still need surgery to control their condition but most find relief through treatment</td>
</tr>
<tr>
<td>How do they work?</td>
<td>How quickly can they provide relief?</td>
<td>What are the side effects?</td>
</tr>
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<tr>
<td>Reduce the inflammation in the colon; help to heal the damaged inner intestine (mucosal healing)</td>
<td>4-8 weeks</td>
<td>Headache, nausea, rash</td>
</tr>
<tr>
<td>Reduction of inflammation anywhere in the body.</td>
<td>1-3 weeks</td>
<td>Infection, bone mineral loss, slowing of growth in children, increased appetite, weight gain, and disturbed sleep pattern</td>
</tr>
<tr>
<td>Weaken and suppress the immune system to help reduce long-term inflammation</td>
<td>2-4 months, can be combined with steroids to speed up your response</td>
<td>Infection, fever, chills, sore throat</td>
</tr>
<tr>
<td>Stop the effects of the TNF-alpha protein known to be involved the inflammation process; may provide mucosal healing</td>
<td>2-4 weeks</td>
<td>Infection; allergic reactions such as joint pain; rash or short term fever, heart failure in the elderly (watch out for swollen ankles or shortness of breath); or skin disorders</td>
</tr>
<tr>
<td>Permanently removes the damaged large intestine</td>
<td>immediately</td>
<td>Possible risks with all surgeries; may involve having an external colostomy bag</td>
</tr>
</tbody>
</table>
“Take your medication exactly as your doctor tells you to. It is very important that you do this so your medication has the best possible chance of working.”
Tips for talking with your doctor
Here are some tips to help you talk to your doctor effectively. This may help you to manage your IBD with them.

Take your medication
Take your medication exactly as your doctor tells you to. It is very important that you do this so your medication has the best possible chance of working.

Talk to your doctor
Talk to your doctor about your side effects and how you can manage them - for example, you might be able to change the time that you take medication to a time that suits you better and is more convenient.

Tackle problems
Your doctor can give you advice on managing all of your symptoms such as bloating, wind, and even stress. Talk to them about any aspect of your health.

Track your symptoms
Your symptoms might change between visits with your consultant or nurse so it might be useful to keep a symptom diary where you can record things such as bowel movements, meals and weight. This will help you give your doctor a more accurate picture of your health and help you play a more active role in managing your IBD.
The importance of support

Coping with your disease will be a lot easier if you let loved ones support you. Those that are closest to you will want to understand what you are going through and learn how they can help you. Be honest about your condition and how you are feeling about it. The more they understand about your illness, the better support they can be to you. It can help you feel less isolated.

Coping with emotions - Talking with friends and family about your IBD

Being diagnosed with a chronic illness can be scary and it may have a big effect on all aspects of your life. Accepting the long term nature of the disease and the changes you will need to make in your lifestyle may be difficult. Having a better understanding of what IBD is and how it is treated may help you to cope. You might also find it helpful to be open with other people about what you are going through.

It can sometimes be difficult to talk about IBD to other people, including family, friends and even healthcare practitioners. However, you must not let embarrassment isolate you, and stop you from talking about your IBD.

When you decide to talk about your IBD, try to think about how you can help the other person understand your condition and help them to give you the support that you need. It may help to remember the following:

- Think about how much you are willing to share
- Think about how much the other person is able to manage
- Decide what is/is not appropriate to talk about

Relationships and IBD

If you are already in a relationship or if you have just met someone new, you may be wondering how to cope with IBD while being in a relationship. Deciding whether and when to tell and what to say is not easy and there is no right or wrong answers. You may fear being rejected but just remember that sometimes when people react negatively, it may because of their own embarrassment, shock or hurt.
If you are in an existing relationship, remember that your partner cares about you and will want to know what you are going through so that they can provide whatever care and support that they can.

The question of what to tell a new partner about IBD will always be a tricky one. Only you will know exactly when, what and how to tell them. Once you have gotten to know the other person a little better you may feel secure enough to talk to them about a personal issue. Telling your boyfriend or girlfriend about your IBD may help to relieve your anxiety and help them to understand you more. Try to be upfront and honest about your condition. Explain what it is and how you are dealing with it. You may even find it is helpful to give them a booklet like this where they can learn more about IBD.

“You may fear being rejected but just remember that sometimes when people react negatively, it may because of their own embarrassment, shock or hurt.”
“Try to get as much exercise as you feel able for because as well as helping you physically, exercise will also help you emotionally.”
Exercise and IBD

People with IBD can do all kinds of different exercises; but be aware of your own limits and listen to your body. Remember it is important to talk with your healthcare professional before you begin to exercise.

When you are having a flare up, your body will not be able to do as much as when you are in remission. Wait until your flare up is under control, you are eating regular meals, and the joint pain you may have been experiencing is gone and you have more energy.

When your IBD is under control, regular exercise can be good for you - it will help make sure that your body is working the way it should and will generally make you feel better.

Try to get as much exercise as you feel able for because as well as helping you physically, exercise will also help you emotionally. Staying physically active will help to:

- improve your mood
- reduce your stress levels
- increase feelings of energy; and
- Improve the way you feel about yourself

You don’t have to join a gym or invest in expensive equipment- walking to school, college or work is a great start, and it’s free!

What type of exercise is best?

As with everything, there is no one-size-fits-all solution so there is no single exercise that is right or wrong. Find an exercise that you enjoy you are more likely to stick with it.
Are there any risks?

When you are exercising, you are at risk of becoming dehydrated, something that it’s important to avoid when you have IBD. Don’t worry though; this can be avoided by drinking lots of water before and during exercise. Make sure you don’t push yourself too hard. Be aware of your temperature- you are more likely to get dehydrated if you get too hot or are active on a very warm day. Remember that IBD is a chronic illness, so it is important to talk with your healthcare professional before you begin to exercise.

Smoking and IBD

While the exact cause is unknown, we know that certain environmental factors play an important role in the onset of IBD and smoking is one of those factors. Smoking affects people with Ulcerative Colitis and Cohn’s Disease in different ways and it is always advised that you do not smoke if you have either of these conditions.

Smoking can increase the frequency of flare ups and can reduce the effects of some treatments. For advice on how to give up smoking speak to your doctor, IBD nurse, consultant or pharmacist.

You can also call the National Smokers Quitline on CallSave 1850 201 203 for information, advice and support on quitting.

Drinking and IBD

For some people, drinking alcohol can make their symptoms worse. If you have IBD, alcohol can irritate the lining of the digestive tract and can also cause malabsorption (difficulty digesting or absorbing nutrients from food) and bleeding.
“Make sure you don’t push yourself too hard. Be aware of your temperature—you are more likely to get dehydrated if you get too hot or are active on a very warm day.”
It’s also possible that the medications that you are taking might react badly with alcohol so be sure to discuss this with your doctor. With some types of medication, you are not allowed to have any drink at all as it can cause you to feel ill or vomit. Drinking excessive amounts of alcohol can also affect your liver and lead to liver toxicity, depending on what meds you are taking.

**Sex and IBD**

It is possible to have a normal sex life with IBD. However, your IBD may interfere from time to time.

**During a flare**

- You may feel too unwell to have sex.
- If you have diarrhoea, oral contraception (the pill) may be less effective so you should use other barrier methods as a precaution.
- Fistulas can make sex painful and uncomfortable.

If you have any concerns, talk to your doctor, IBD nurse or consultant.

“It is possible to have a normal sex life with IBD. However, your IBD may interfere from time to time.”
Pregnancy and IBD

Many patients with IBD have normal fertility and can expect a normal pregnancy, childbirth and development of a healthy baby.

However, where issues may arise are if you undergo a ‘j-pouch’ otherwise known as pouch surgery or if you have Crohn’s disease, as the abdomen can block the fallopian tubes or may make intercourse painful. Another issue that can occur in fertility is if a man is taking the 5ASA drug sulphasalazine (Salazopyrrin) as his sperm count can decrease, however this is reversible and sperm count will return to normal when stopped.

There is a good chance you can remain well throughout a pregnancy if you have conceived when your disease has remained inactive. However, if your disease is active at the beginning or you suffer flares during pregnancy there is a risk that this may cause a low birth weight or the baby may be premature.

Like any other women planning for a pregnancy, folic acid supplement is advisable before conception and for the first twelve weeks of pregnancy to reduce health risks in the baby. Fish oil is also helpful and can prove to be of some benefit to a pregnant mother with IBD.

As with all pregnancies investigations which involve x-rays and radiation should be avoided unless absolutely essential, this includes CT-scans.

Medication and Pregnancy

Most of the medications used to treat IBD, with the exception of methotrexate, may be used in pregnancy and keeping disease under control minimizes complications. It is important to keep your Ulcerative Colitis or Crohn’s disease under control whilst you are pregnant as the disease may do more harm to the baby than the medicines. However, you should discuss this with your healthcare professional or with your hospital prior to conception.

Drugs such as Aminosalicylates (5 – ASAs), corticosteroids and Immunosuppressants have been taken by women during pregnancy for years and are thought to have an acceptable safety profile. However as there is still relatively little known about this area it is best to check with your healthcare provider and hospital on your medication during pregnancy and before conception.

Drugs to avoid during pregnancy include antibiotics, biologics, certain antidiarrhoeals and antispasmodics.
“Like any other women planning for a pregnancy, folic acid supplement is advisable before conception and for the first twelve weeks of pregnancy to reduce health risks in the baby.”
Breastfeeding
Breastfeeding is not recommended when taking Azathioprine, Ciclosporine, Biologics or Methotrexate. Based on past experience corticosteroids and 5-ASAs while breastfeeding.

Delivery
Your obstetrician will decide to deliver the baby by vaginal delivery or via caesarian section, however, in most cases a normal vaginal delivery can happen.

IBD and bowel cancer
Patients with longstanding Ulcerative Colitis and Cohn’s disease affecting the colon can be at risk of developing bowel cancer. Another risk factor includes how much of the colon is affected. However, for many people with IBD there is little or no greater risk of developing bowel cancer than in the general population. A regular colonoscopy to check for pre-cancerous changes is particularly important for patients with IBD and often biopsies are taken in order to reveal any early warning signs that cancer may develop.

Three main ways that may help to reduce the risk of bowel cancer in IBD patients are taking regular medication, visiting your doctor regularly and having regular colonoscopies. Physical activity and managing your diet may also help.
The cost of IBD

IBD requires ongoing medical care in order to manage the disease and ensure you can maintain a good quality of life. As such, it is important for you to be aware of the possible direct financial costs to you.

Tax Relief
You may claim tax relief on a Form MED 1, at the standard rate of tax for certain medical expenses that you pay. Most medical expenses, with some exceptions, qualify for relief.

You cannot claim relief for any money you have spent that has been or will be paid back to you for example, Aviva Health, Quinn Healthcare, VHI or a health authority. Neither can you claim back any money where you have received or will receive compensation. For more information, see www.revenue.ie

Prescriptions
Under the Drugs Payment Scheme (DPS) you will not have to pay more than €132 a month (from January 2010) for approved prescribed drugs, medicines and certain appliances for use by yourself and your family. You must be ordinarily resident in Ireland to qualify for this scheme.

When you register for the scheme, your local health office will issue a plastic swipe card for each person named on the registration form. You should present this card whenever you are having prescriptions filled. Further information is available from your Local Health Office, details of which can be found at www.hse.ie.

Insurance
When looking for an insurance policy, be aware that the cover and benefits provided by different insurance groups will vary. It is important to read the fine print so you can be sure that the policy is both good value and meets your needs. Make sure that your policy covers IBD before signing up for it to make certain that the insurance group will cover the claims that you submit. Details of Irish health insurance providers can be found on the Irish Health Insurance Authority’s website, www.hia.ie.
Common medical terms used in IBD

It is important to ask your doctor and other health care professionals to explain anything you do not understand. To help you learn more about IBD, below are some medical terms that are frequently used by doctors, nurses and other healthcare professionals when talk about IBD.

**Acute**
Less than six weeks versus chronic which means greater than six weeks

**Auto-immune disease**
An illness that occurs when the body tissues are attacked by its own immune system. The immune system is designed to “seek and destroy” disease in the body, including infectious agents. Patients with autoimmune diseases frequently have unusual antibodies circulating in their blood that target their own body tissues.

**Anti-TNF-alpha**
This is a newer type of drug, called a biologic, used for treating severe IBD, especially Crohn’s. These drugs work by blocking the effects of TNF-alpha, an inflammatory substance in the blood produced in excessive amounts in IBD.¹

**Anus**
The anus is the opening at the lower end of the gastrointestinal tract, at the end of the rectum. The anal canal is a short passage which connects the anus to the rectum.

**Biologics**
Biologics form the newest group of drugs to be used in IBD. They include infliximab and adalimumab. They work with the immune system to block chemicals that cause ongoing inflammation.

**Biopsy**
This involves a small piece of tissue taken from the body for examination under a microscope.

**Bowel**
This is another name for the intestines – the small bowel (duodenum, jejunum and ileum), and the large bowel (colon).

**Chronic**
Originating from the Greek word ‘ongoing’. This means a chronic illness is ongoing or continuing.

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Colon (the large intestine)
The colon is the part of the intestine that follows on after the small intestine. The colon leads to the rectum and the anus. The function of the colon is to absorb water. It is about 1.5 metres long. The colon consists of the:

- Caecum
- the ascending (right side)
- the transverse (top)
- the descending (left side);
- and the sigmoid.

Colonoscopy
A colonoscopy is an examination of the rectum, colon and last part of the small intestine using a lighted, flexible tube called a colonoscope which is inserted through the anus.

Enema/suppository
Liquid or foam inserted into the large bowel through the anus, for diagnosis or treatment.

Fistula
A fistula is an abnormal channel between two loops of intestine, or between the intestine and another organ, or between the intestine and the skin, or rectum and the skin.

‘Flare Up’
Also known as a relapse is a return of disease activity after a partial recovery.

Gastroenterologist
A gastroenterologist is a doctor specially trained in the diagnosis and treatment of intestinal disorders, including Crohn’s disease and Ulcerative Colitis.
“It is important to ask your doctor and other health care professionals to explain anything you do not understand.”
Haemorrhoids
Haemorrhoids are swollen veins in or around the anus which bleed easily and can become painful. They are commonly known as piles.

Ileitis
Inflammation of the Ileum. A term used for Crohn’s disease of the ileum.

Ileum
The lower part of the small intestine, which joins the colon at the ileocaecal valve.

Ileal pouch – anal anastomosis (IPAA)
A surgical operation for Ulcerative Colitis after removal of the colon. An internal pouch is made from the ileum and attached to the anus. This means you pass stools through the anus in the usual way. Sometimes referred to as restorative proctocolectomy.

Infusion
Infusion is a procedure to give a drug or a solution directly into the bloodstream. The fluid flows from a sterile bag through plastic tubing and a small needle into a vein.

Mucosa
The inner lining of the intestines.

Mucus
Mucus is a slimy white jelly-like fluid produced by the lining of the intestines. People with Ulcerative Colitis often have a lot of mucus in their stools.

Non-steroidal anti-inflammatory drugs (NSAIDs)
Non-steroidal anti-inflammatory drugs (NSAIDs) are painkillers often used for arthritis. These include drugs like ibuprofen and diclofenac. They can cause flare-ups in some people with IBD.

Rectum
The last part of the colon.

Remission
A period of good health, free of active disease with few or no symptoms.

Resection
Surgical removal of a diseased segment of Intestine.

Stoma
A stoma is a surgically constructed opening of the intestine onto the abdominal wall over which a bag can be fitted and sealed to the skin.

Stricture
Abnormal narrowing of the bowel due to inflammation and scarring.
For more information about IBD visit www.getgutsy.ie