The ins and outs of

Inflammatory Bowel Disease

Second edition

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Introduction

If you have inflammatory bowel disease (IBD) this booklet will help you to understand your condition and the treatments that are commonly used to manage it. This booklet will also cover topics around living with IBD such as proper nutrition and holiday travel advice. There's also a handy section on how best to prepare for your doctor appointments. If you have any questions about your condition or its treatment, make sure you speak to your GP or specialist.

About the digestive system

The digestive system starts at the mouth finishing at the anus. The main role of the digestive system is the breakdown and absorption of nutrients thereby providing the body with essential energy requirements.

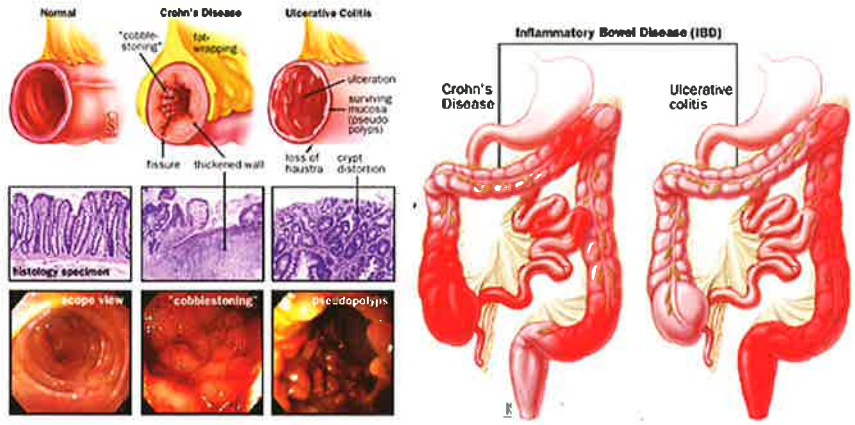
From the mouth, food passes down the oesophagus into the stomach. In the stomach, food is mixed with digestive juices which start breaking it down to allow it to be absorbed. Food then leaves the stomach and enters the small bowel in which the majority of absorption of nutrients takes place.

As the digested food comes to the end of the small bowel, most of the useful nutrients have been absorbed through the bowel wall leaving a liquid mixture of waste products. This solution enters the large bowel (colon and rectum) where fluid is reabsorbed thereby converting the waste products into a formed stool. The rectum is simply a reservoir that holds stool until it can be evacuated.

Understanding Inflammatory Bowel Disease

Inflammatory bowel disease is a chronic (long-term) condition in which various sites in the gastrointestinal tract become inflamed. The condition is lifelong and episodic. It is characterised by periods of remission, when the disease is less active and people have no symptoms or milder symptoms, and periods of relapse or disease flare-ups, when the condition is more active and there are more severe symptoms. It is quite common to feel tired, experience fevers and lose your appetite. Some people may experience severe or persistent diarrhoea, in which blood and/or mucus may be present, as well as abdominal pain and weight loss. In addition people may experience symptoms in parts of the body outside of the gastrointestinal tract, including the joints, eyes and skin.

There are two types of IBD – ulcerative colitis and Crohn's disease. Your doctor will probably have explained to you which type of IBD you have.



Adapted from http://cceffect.org and https://ihaveulcerativecolitis.wordpress.com [both accessed July 2015]

Ulcerative colitis

Ulcerative colitis affects the colon, and is characterised by inflammation of the inner lining (mucosa) of the bowel wall. The inflammation always commences in the rectum but it can sometimes extend throughout the entire colon. The inflammation reduces the ability of the colon to reabsorb fluid from the faeces which causes diarrhoea. Inflammation in the rectum can lead to a sense of urgency to have a bowel movement.

Crohn's disease

Crohn's disease can affect any part of the gastrointestinal tract from the mouth to the anus, but the areas most commonly affected are the small intestine and the colon. Inflammation can extend through the whole thickness of the bowel wall, not just the mucosa. Unlike ulcerative colitis, the areas of inflammation may not be continuous and instead form "skip" lesions with areas of normal bowel between them.

Causes

The exact cause of IBD is unknown. One explanation is that genetic and environmental factors result in an abnormal immune response which causes the body to attack your own cells in the gastrointestinal tract. Inflammatory bowel disease is not thought to be caused by diet or stress and is not contagious.

FAQ: I have Crohn's disease. Will my children develop IBD?

We know that genes play an important role in the development of IBD. It is therefore, unsurprising that people who have IBD sometimes worry about the risk of one of their children also getting the disease. However, research has shown that there are multiple genes involved. It is also important to remember that many other factors are involved in the development of IBD.

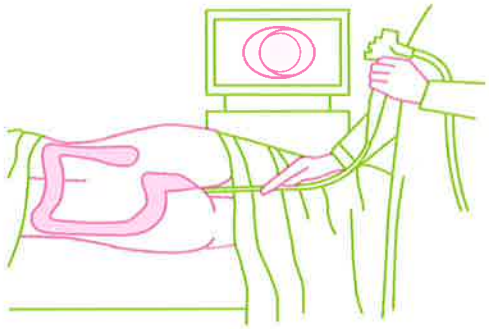
Currently, the risk of an offspring also developing Crohn's disease is probably in the order of 5-10%,[1] while it is a little lower for ulcerative colitis.

Investigations and diagnosis

There is no single test that can be used to definitively diagnose IBD. The disease can sometimes be difficult to diagnose, as many of the symptoms of IBD can also occur with other conditions such as irritable bowel syndrome or infectious gastroenteritis. Some or all of the following tests may be conducted as part of the diagnostic process:

- Stool sample – to rule out gastroenteritis and to check for inflammatory faecal markers such as calprotectin
- Blood test – to check for anaemia (caused by bleeding in the bowel) and to assess signs of inflammation via inflammatory markers such as C-reactive protein
- Colonoscopy or sigmoidoscopy – an examination of the bowel using a long flexible tube inserted via the anus
- Gastroscopy – an examination of the upper gastrointestinal tract using a long flexible tube inserted via the mouth
- Histology – tissue biopsies obtained during a colonoscopy or gastroscopy is examined for microscopic changes of IBD
- Medical imaging – Magnetic resonance imaging (MRI), ultrasound scan, computed tomography (CT) scan and small bowel barium x-rays.

Procedure of colonoscopy



A tiny video camera at the tip of a colonoscope transmits images to a television monitor so that your doctor can look closely at the inside of your colon.

It is often necessary to do several tests to ensure an accurate diagnosis, and to distinguish Crohn's disease from ulcerative colitis. However, about 5-15%[2] of patients with IBD will have features of both conditions. When a clear distinction between the two conditions cannot be made, patients are diagnosed as having "IBD unclassified or IBD-U".

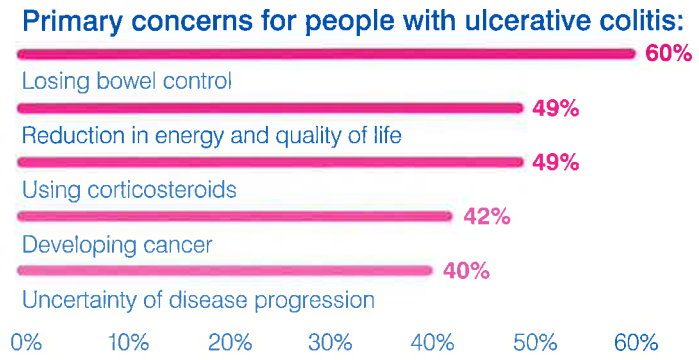
Ref 1. Crohn's and Colitis Australia. Frequently Asked Questions. https://www.crohnsandcolitis.com.au/about-crohns-colitis/frequently-asked-questions/ [accessed June 2015]

Ref 2. GESA guidelines. Australian Guidelines for General Practitioners and Physicians Inflammatory Bowel Disease Third Edition 2013. http://www.gesa.org.au/files/editor_upload/File/Professional/33859_b-2.pdf [accessed June 2015]

Impact on general health

Ulcerative colitis and Crohn's disease frequently begin in adolescence or young adulthood. They are lifelong conditions, and individuals with these conditions are understandably concerned about the possible impact on their general health and life expectancy, and about the effect on their ability to lead normal lives including participation in everyday activities like working, maintaining relationships, travelling and having a family.

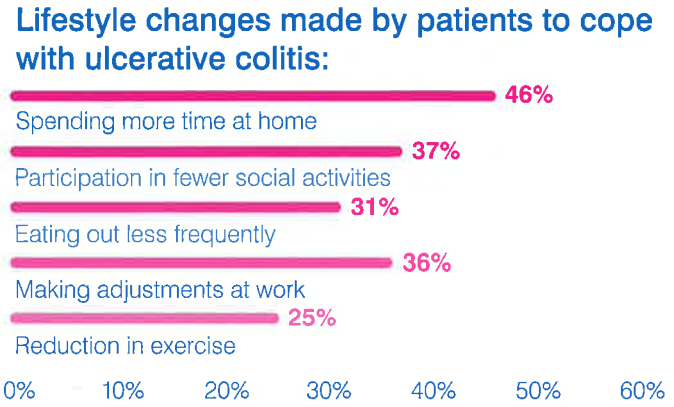
A survey of 1595 patients conducted by the Crohn's and Colitis Foundation of America provides an insight into the effects of ulcerative colitis on patients' lives:



Adapted from Inflamm Bowel Dis 2006;12:1107-1113

Generally, when IBD is well-managed, life expectancy is not affected. At any one time the majority of patients will be either in remission or experiencing only mild disease activity. The majority of people with IBD are able to live normal lives including working, marrying, having children, engaging in sport and recreational activities and travelling.

However, even for people who are well managed and in remission, the threat of their condition flaring again never goes away. Knowing this is often a burden and can impact on the quality of life of people living with IBD.



Adapted from Inflamm Bowel Dis 2006;12:1107-1113

Possible complications

Complications can sometimes occur in patients with IBD, with some occurring in the gastrointestinal tract and others occurring outside the gastrointestinal tract. Some complications are more serious than others.

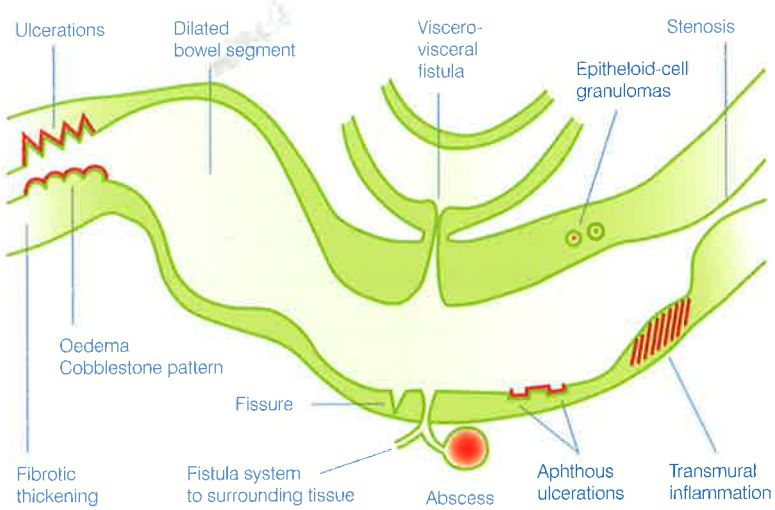
The more common complications include:

- Bowel stricture (narrowing) – a complication of Crohn's disease. Swelling and scar tissue results in thickening of the bowel wall and narrowing of the intestinal passage. If the strictures are severe, it can lead to bowel obstruction (blockage) which may require surgery.
- Fistula – occurs in Crohn's disease and is an abnormal connection between the bowel and other body structures, such as the skin or other organs in the abdomen or pelvis
- Haemorrhage – excessive bleeding may necessitate admission to hospital

FAQ: Does partial obstruction always lead to surgery?

No. Only in severely obstructed patients is surgery necessary. In many less severely obstructed patients, medical treatment alone will reverse the partial obstruction and relieve the symptoms.

Macroscopic and microscopic changes in the gastrointestinal tract that can happen in Crohn's disease



Other more serious complications, although rare, include:

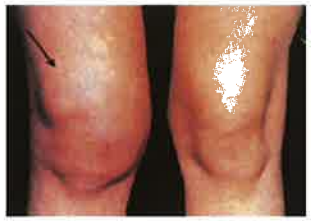
Toxic megacolon – this occurs when the large intestine dilates as a result of severe inflammation, resulting in a reduction of normal bowel contractions. Immediate medical attention is needed to prevent the intestine from rupturing. Although rare, it tends to be more common in ulcerative colitis patients than Crohn's disease patients.

Perforation of the bowel – this occurs when chronic inflammation and ulceration leads to holes developing in the bowel wall. This means that intestinal contents and bacteria can spill into the abdomen and cause infections.

Colorectal cancer – the risk of developing bowel cancer is proportional to the duration of disease and the extent of colon affected. The risk appears to be slightly higher in patients with ulcerative colitis than in those with Crohn's. Overall however, the risk of bowel cancer is low in IBD.

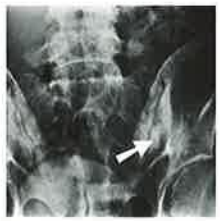
Inflammatory bowel disease can also cause complications outside the gastrointestinal tract. These can include:

- Joint inflammation
- Inflammatory skin and eye conditions
- Bone loss – osteoporosis
- Liver disease
- Blood clots in veins and arteries

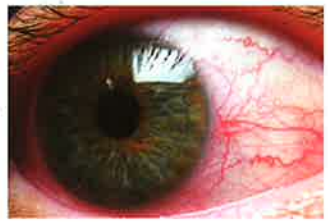


IBD arthropathy

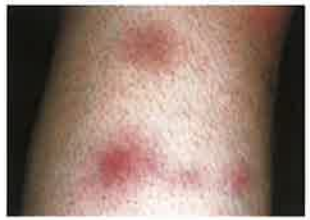
Sclerosing cholangitis



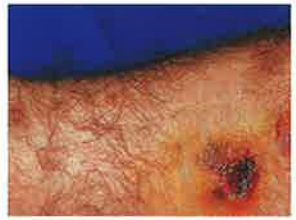
Sacroileitis



Episcleritis



Erythema nodosum



Pyoderma gangrenosum

FAQ: How can I avoid serious complications?

With proper treatment, most patients do well and do not develop any serious complications. Early recognition, proper medical treatment and good nutrition are the most important factors to prevent complications of IBD.

Treatment of Inflammatory Bowel Disease

There is no medical cure for IBD although appropriate medical treatment can help manage symptoms in most cases. The goals of IBD management are to get people well (induce remission), keep people well (maintain remission) and to prevent complications from the disease. The mainstay of treatment for IBD is medication. Surgery may also be an option for some people with IBD.

It is likely that you will require two different treatment strategies to manage your disease. Firstly you will need a medication that will help relieve symptoms and also heal the mucosa, hence reducing the chances that complications may develop. Once in remission, the goal is to reduce the risk of experiencing repeated flare-ups so you will need to take a maintenance agent. This can be the same medication that you have been taking already but at a reduced dose, or it can be a different drug. You may need to trial different medications or dosage levels to find the treatment which controls your condition best.

Medications for IBD work in different ways. Some are used to reduce inflammation, others modulate or suppress an overactive immune system and still others are used to treat the symptoms of IBD such as diarrhoea and pain.

Medications for IBD

The choice of medication will depend on the goal of treatment (induce or maintain remission), the extent and severity of the disease, previous response to treatment as well as any presence of complications.

The main groups of medications used in the management of IBD are:

- aminosalicylates
- corticosteroids
- immunomodulators
- biological agents

Aminosalicylates

Aminosalicylates (also known as 5-ASAs) are anti-inflammatory drugs. They are mostly used in people with ulcerative colitis, although some people with Crohn's disease may also benefit from 5-ASAs. They are used in the treatment of active attacks, and also during periods of remission to prevent flare-ups.

Aminosalicylates are often used for the treatment of mild to moderate symptoms of IBD. They can be taken orally and there are also topical formulations (enemas or suppositories) which are administered rectally.

There are a number of 5-ASA products available in Australia. The first 5-ASA was sulfasalazine. Since then, a number of newer 5-ASAs have been made available and they include mesalazine, balsalazide and olsalazine.

Corticosteroids

Corticosteroids (steroids) can be very effective in reducing inflammation during an active attack of ulcerative colitis or Crohn's disease; however, they are generally only used when symptoms of IBD are moderate to severe.

Steroids can be taken orally as tablets, or given as an intravenous injection (in hospital) if the inflammation is more severe. They can also be administered topically (as an enema or suppository) if the inflammation is predominantly in the rectum and lower part of the colon.

Steroids should be used for the shortest time possible due to side effects. Side effects are more likely to occur with systemic (oral or intravenous) administration than with topical administration. Once in remission, which usually takes 7-14 days, the steroid dose is reduced gradually according to the severity of the disease and how well you are responding.

Steroids that are currently used for IBD include prednisolone, budesonide and hydrocortisone.

Immunomodulators

Immunomodulators also reduce inflammation but they target your immune system rather than directly treating the inflammation. They work by modulating or suppressing the immune system to control inflammation. Immunomodulators are often used when the disease is moderate-to-severe, or when the disease flares up again after steroids are stopped or reduced.

Azathioprine and 6-mercaptopurine are two commonly used immunomodulators for IBD. Methotrexate is an agent that may be helpful in patients who do not respond to or can't tolerate azathioprine or 6-mercaptopurine. Cyclosporin and tacrolimus are other agents that are sometimes used but they are generally reserved for disease that is very severe and unresponsive to steroids.

Biological agents

Biological agents are the newest groups of medications used in the management of IBD. These medications target specific molecules thought to play a key role in the inflammatory response. In Australia, biological agents can only be prescribed by a specialist gastroenterologist.

Biological agents are usually reserved for people with moderate to severe ulcerative colitis or Crohn's disease who do not respond to or cannot tolerate other treatments. The biological agents currently available for IBD include infliximab, adalimumab, and vedolizumab.

Drugs used to treat symptoms of IBD

In addition to controlling inflammation, some medications may help to relieve the symptoms associated with IBD such as diarrhoea and pain. Always talk to your doctor before taking any over-the-counter medications.

Fibre supplements

A fibre supplement may help to relieve mild diarrhoea in IBD by adding bulk to your stools.

Antidiarrhoeals

An antidiarrhoeal such as loperamide may be helpful in more moderate diarrhoea. Antidiarrhoeals should be avoided in patients with severe IBD due to the risk of complications. Antidiarrhoeal medications should only be used after discussion with your doctor.

Bile salt binders

Bile salts that pass into the large bowel due to surgical removal of, or damage to, the distal small bowel may cause diarrhoea. Cholestyramine binds to bile salts and may be used to relieve diarrhoea due to bile salt malabsorption.

Analgesics (pain relievers)

Pain relief in IBD can be challenging as some analgesics can make your disease worse. For mild pain during an acute flare-up, paracetamol is sometimes used. Other analgesics such as non-steroidal anti-inflammatory drugs (NSAIDs) should be avoided as they can induce or worsen flares of IBD. The use of opiates such as codeine and morphine should be minimised as chronic use may be associated with numerous side effects, especially constipation and physical dependence.

Surgery

Surgery in IBD is generally reserved for patients who are not responding adequately to medical treatment, or to manage complications arising from the disease such as strictures, abscesses or bleeding.

In Crohn's disease, removing part of the inflamed intestine may improve symptoms but it is not curative. The disease usually returns after surgery, but recurrence can be prevented or delayed by post-operative medications. In patients with severe ulcerative colitis, surgery to remove the colon can cure the disease but patients will have to cope with both the physical and psychological consequences of surgery such as an ileo-anal pouch, or more rarely a permanent stoma.

While surgery may not be appropriate for everyone, it remains an important part of the management of IBD when medical therapy is ineffective or not tolerated.

FAQ: My doctor says that I should have surgery. Did I fail at managing my disease?

No. Sometimes, medicines can no longer control your symptoms. Surgery can give lasting relief from symptoms and may reduce or even get rid of the need for medicine. Not every type of surgery is right for every person. People faced with the decision to have surgery should get as much information as they can from their doctors, nurses, and other patients.

Living with Inflammatory Bowel Disease

The majority of people with IBD are able to live normal lives including working, marrying, having children, engaging in sport and recreational activities and travelling.

Eating choices

It is important for people with IBD to have a healthy diet to prevent weight loss and nutritional deficiencies that may result from the condition. Some people may need to take nutritional supplements. In children with IBD, diet is particularly important, as children are especially susceptible to nutritional deficiencies and their growth may be adversely affected.

Diet and food do not cause IBD and there is not enough evidence that special diets are effective in treating active IBD. However, making adjustments to your diet may help you manage your symptoms better. During a flare-up, some people find that a bland, low-fibre diet is easier to tolerate than a rich diet with lots of fibre or spices. Low-fibre diets tend to result in less bowel secretions and contractions which may help control symptoms such as abdominal cramps and diarrhoea.

FAQ: I have heard a lot about the low-FODMAP diet. Would that be suitable for me?

Speak to your doctor about whether this is suitable for you. A low-FODMAP diet may help manage some of the symptoms of IBD such as wind and abdominal cramps. It does not treat the inflammation of IBD itself. FODMAP stands for a group of carbohydrates, Fermentable Oligosaccharides, Disaccharides, Monosaccharides and Polyols that are poorly absorbed in the small intestine. When patients with Crohn's or ulcerative colitis are in remission but are still symptomatic, they may have a coexisting irritable bowel syndrome or dietary intolerances to FODMAPs. A low-FODMAP diet avoids foods that can cause diarrhoea, constipation, gas, bloating and abdominal pain.

FAQ: What can be done to prevent and manage malnutrition?

A combined approach of medical treatment and replacement of nutrients is usually indicated. If patients are deficient in vitamin B12, this vitamin can be given by injection. If there is a deficiency in iron, this mineral can be given in tablet, liquid form or by injection. Rarely, hospitalised patients can be given intravenous fluids sometimes in the form of Total Parenteral Nutrition (TPN) where all nutrients are supplied by the intravenous route.

Holiday travel

Most patients with IBD are able to have enjoyable holidays. Plan your trip well. It is better to travel when your condition is stable. Ensure you have adequate travel insurance and obtain a letter from your GP or specialist outlining your medical history and all medications you are currently taking. Consider your travel destination to be sure that you are comfortable with all the necessary amenities.

Ensure you take an adequate supply of medication with you. Keep your medications in their original packaging in case you need to show them at customs.

Check with your airline before you fly whether you can carry your medications in your hand luggage, especially if you need to take syringes. Smartraveller.gov.au is a useful travel advice website to check specific country requirements.

Preventative vaccinations

Many therapeutic regimens for IBD include immunosuppressive therapy or combinations thereof. Because of the way these medications work, there is a higher risk of infection. Some of these infections can be prevented by vaccinations which are recommended to all patients with IBD. This should be discussed with your doctor, ideally soon after you are diagnosed with IBD.

Special situations

Fertility, pregnancy and breastfeeding

Most people with IBD are able to have children and raise a family. Inflammatory bowel disease itself when in remission usually does not affect fertility in males or females although some IBD medications can cause fertility issues which are reversible on discontinuation.

As far as possible the timing of pregnancy should be planned so that it occurs during a period when the disease is under control. Before becoming pregnant, these plans should be discussed with your doctor.

Most women with IBD have normal pregnancies and normal deliveries although added challenges can occur especially for women with Crohn's disease, especially when the perianal region is involved. These potential issues should be discussed thoroughly with your clinical team, including your obstetrician.

There does not appear to be any risk that IBD will worsen as a result of breastfeeding. Breastfeeding is encouraged due to the benefits to both mother and child. It is, however, very important to discuss suitable treatment options for women electing to breastfeed, as some medications are excreted through breast milk.

FAQ: Can inflammatory bowel disease affect my menstrual cycle?

Yes. Some women with IBD feel worse right before and during their menstrual periods than at other times. Diarrhoea, abdominal pain, and other symptoms can be more severe during these times. Women with IBD and their doctors should keep track of these monthly changes in symptoms. This will prevent overtreating the disease. Conversely, if you have not been eating well and have lost a lot of weight due to your IBD, your menstrual cycles can become irregular.

Children and adolescents

Inflammatory bowel disease can also occur in children. In fact, 25 % of patients with IBD first present in childhood/adolescence ie. before the age of 20.[3] The spectrum of the disease and complications are similar to adults for both ulcerative colitis and Crohn's disease.

Childhood and adolescence is a very important time for growth (ie. achieving one's final height), pubertal development and bone health. Poorly controlled IBD can have a major impact on these time-critical events of life and hence emphasis is placed on early diagnosis followed by appropriate treatment to control the disease. Good nutrition is a very important component in the management of children with IBD to support normal activity and growth. During flare-ups, a high protein diet may help. Meat and dairy products are a good source of calories and protein. For some children who have trouble eating, special liquid diets can be used to support their nutritional needs.

Apart from the challenges of various facets of physical development, adolescence can also be an emotionally difficult time for patients with IBD. Some youth may experience low mood and self-esteem due to their chronic gastrointestinal symptoms. This can sometimes lead to problems at school, peer relationships and social isolation. Social and emotional support is paramount in children with chronic disease. Treatment adherence can also be a major issue with adolescents. Parents and treating physicians need to be vigilant of this.

Another stressful event that is sometimes experienced by patients with IBD and their families is the transition and transfer of their care. This is a process when patients are equipped to move on from under the care of the Paediatric Gastroenterology team to the Adult team. This is a period that needs to be dealt with sensitively and is usually a slow gradual informative process, in line with the patient's level of readiness, maturity to move on and also complexity and stability of her/his disease.

Ref 3. Day AS et al. World J Gastroenterol 2012;18:5862-5869

Psychological issues

While stress does not cause IBD, it can be a trigger for flare-ups in some people with IBD. For people with IBD, the chronic and unpredictable nature of the disease can cause a range of psychological concerns such as fear of losing bowel control, fatigue, poor body image and social isolation.

As is the case with most chronic illnesses, people with IBD are more likely to suffer from anxiety and depression than the general population. These symptoms also tend to be more severe during flare-ups. There is also some evidence that coexisting depression can make managing active disease more challenging.

As a result, it is important for patients and family members to be mindful of any mood changes. If you notice any mood or anxiety issues, it is important to seek professional help from your doctor who may refer you to a psychologist or psychiatrist if needed. Treating IBD is not always as simple as just treating the disease in the gut; more frequently, treatment is multi-disciplinary with a variety of health professionals working together to help manage your condition.

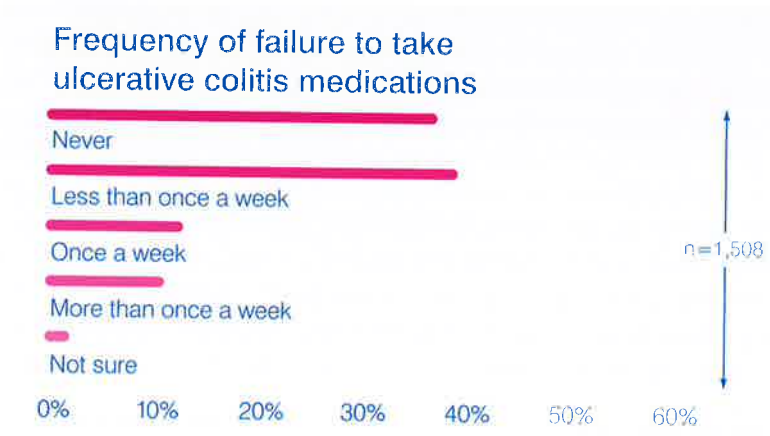
Adhering to treatment

Good management of IBD is aimed at prolonging periods of remission, preventing relapses and shortening the duration of active disease flares. This may also help prevent or delay the onset of further complications arising from the disease. As there is no medical cure for IBD, it is important to manage the condition throughout both active flare-ups and periods of remission. It is important to keep taking your medications during periods of remission, even if you feel well as the underlying disease is still present. Do your best to adhere to the treatment regimen recommended by your doctor during both active disease and periods of remission. There is evidence that IBD patients who do not adhere to their recommended treatment are up to 5 times[4] more likely to have a flare of their disease than compliant patients.

Patients who are non-adherent to their IBD medication have a 5-fold[4] greater risk of flaring than adherent patients.

It can sometimes be difficult to stick with the treatment your doctor has recommended. Some people also feel uncomfortable about the idea of taking medication long term. It is important to have good communication with your doctor, so that you understand exactly why you are taking the prescribed medication, and to discuss any concerns that you may have regarding your treatment plan and the condition itself. People's lifestyles can also make adherence to recommended treatment difficult. If you have a busy social or working life, it can be hard to remember to have your medication with you when you are out, and of course it is not always convenient to use some topically administered drugs such as enemas. Again, these issues should be raised with your doctor so that you can devise strategies and treatment plans to deal with them. Other factors that can contribute to non-adherence include a poor understanding of the disease, forgetfulness, frequent administration and complex medication regimens, and fear of long-term side effects of medications.

In a survey of over 1500 ulcerative colitis patients, 65%[5] reported failing to take their medication as prescribed.



Ref 4. Kane SV. Patient adherence in inflammatory bowel disease. Gastroeneterologu & Endoscopy 2007 (special edition): 68-74. http://www.gastroendonews.com/download/adherance_gense07WM.pdf
Ref 5. Loftus EV. Inflamm Bowel Dis 2006;1107-1113

Steven's story

Initially, when the symptoms began, coeliac disease came to my mind. Both my mother and my uncle had been diagnosed with the disease years ago, and I thought that all I would have to do to get better was to change my diet and get on with my life. Unfortunately for me, after many tests, doctors' appointments and much medication, I was diagnosed with ulcerative colitis instead. I had never even heard of the condition before the diagnosis, but by that time I didn't care what it was, so long as there was a way to fix it!

I was first diagnosed with ulcerative colitis in the second half of 2011, when I was halfway through the first year of my Psychology degree at Wollongong. To the best of my recollection, I was suddenly symptomatic. I couldn't go further than ten feet from a bathroom at any one time. Needless to say, it was very difficult to get from my place to a doctor, despite my GP being a 2 minute walk from home. I was constantly exhausted, and couldn't concentrate on anything for more than a few minutes at a time. Because of my condition, I was unable to attend university and it was more than a little luck for me to only fail two subjects. Due to the length of my absences, by the time I got back to university it was a little disheartening to find out I was outside the six week limit to medically cover my absences, and thus had to wait at least 6 months to retry the subjects I had failed.

Within weeks of starting medication, I was feeling fantastic! I had forgotten what it was like not to feel tired all the time - normal felt really good. I went back to university and prepared to try my subjects again. As it turns out, that time off from university was a good thing for me, as it contributed to my decision to change my major to History, from which I graduated halfway through 2014.

It has taken a while to find the right medications and get myself completely on top of things, but I'm now back doing the weird hobbies I love, armouring up and fighting in medieval re-enactment combat, as well as catching up on a pile of wood, metal and leather crafting I fell far behind on when I was very unwell. I also work as a historical tour guide and volunteer at the Maritime Museum. Moral of my story?.....once you're on meds that work for you, keep taking them, even when you sometimes feel you don't have to.

Strategies to optimise treatment adherence

Fortunately, there are many things that you can do to help manage your condition and help to maintain your health and quality of life. Some of these things include:

- Keep informed about your condition
- Have ongoing open communication with your doctor and other health care professionals about your condition
- Talk about your treatment options, including different types of medication; where possible, treatment should be individualised to suit you
- Make a commitment to your treatment plan. One way to do this is by writing it down as a contract of terms that you sign together with your doctor
- Make sure your doctor is aware of any concerns you have about your treatment regimen or about your disease
- If you are feeling depressed, discuss this with your doctor and explore options to find help
- Make sure you visit your doctor or specialist regularly, to ensure that any changes in your condition are identified, and that your condition continues to be managed optimally
- Set goals - decide what you want from your treatment and how you will manage your condition, and explore ways to achieve this
- Make sure you understand any instructions that are given to you and have them written down if necessary
- Identify times or situations that are particularly difficult for you, and try to find ways to deal with these
- Keep a readily-accessible file of all the medical information about your condition and update this regularly
- Get support: from family, your nurse practitioner, your doctor and from support organisations

Preparing for your doctor appointments

Because appointments can be short, and there is often a lot of information to discuss, it is a good idea to be well-prepared. Here are some handy hints and tips to help you get ready.

- **Write down any symptoms you are experiencing**. Include any that may seem unrelated.
- **Write down key life changes.** Include any major stresses or recent changes in your life.
- **Make a list of all medications you are taking.** Include over-the-counter medications and any vitamins or supplements.
- **Take a family member or friend along.** Sometimes it can be difficult to remember everything during an appointment and the person who accompanies you may remember something that you missed or forgot.
- **Write down questions to ask your doctor.** List your questions from most important to least important in case time runs out.

Getting support and pulling together

And finally… remember, you don't have to be alone to cope with managing your disease. You can draw from a team of health professionals always willing and ready to give you and your family all the support you need. If you have any further questions about your condition or its treatment, speak to your doctor for more information.

You

Family and friends

CCA

Dietitian

IBD nurse

Psychologist

Gastroenterologist

Pharmacist

General Practitioner

Support Groups

Crohn's and Colitis Australia (CCA)
www.crohnsandcolitis.com.au
IBD Helpline free call 1800 138 029

The Gastroenterological Society of Australia (GESA)
www.gesa.org.au

The Gut Foundation
www.gutfoundation.com

Crohn's & Colitis Foundation of America (CCFA)
www.ccfa.org

National Association for Colitis & Crohn's Disease (NACC)
www.nacc.org.uk

The J Pouch Group
www.j-pouch.org

Mind Over Gut
www.mindovergut.com