



INFLAMMATORY BOWEL DISEASE IN CHILDREN AND ADOLESCENTS

IBD Clinical Nurse Specialists

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INTRODUCTION

Inflammatory bowel disease (IBD) is a term used to describe Crohn’s disease (CD) and ulcerative colitis (UC). Both of these conditions are chronic (long-term) inflammatory conditions that affect the gastrointestinal tract. IBD can cause pain, diarrhoea and other problems for young people. Inflammation causes the mucosal lining of the intestines to become red looking and sore and often causes ulcers to form.

Although CD and UC are two separate diseases, they have similarities in that patients with either disease experience periods of relapses (symptoms become worse/acute) and remissions (you feel better with little or no symptoms). From time to time IBD patients can experience a number of bothersome disease symptoms and occasionally may miss school or college because of their illness, while others have few problems with little or no interference in their lives.

We care for lots of young people with IBD and are frequently asked questions about the disease. The aim of this booklet is to try and help you to understand what IBD is and what we can do to help you live an active life with this condition.

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THE GASTROINTESTINAL TRACT

The gastrointestinal tract is divided into a number of parts, each having a different role to play.

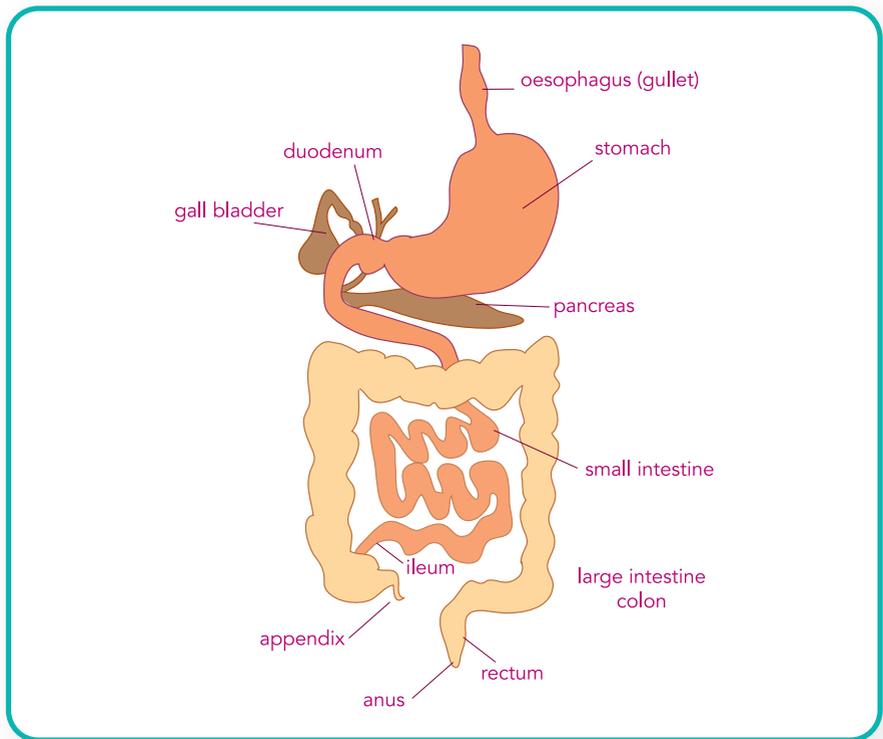
Mouth: Crushes the food into smaller parts and makes it ready for swallowing. This is where digestion starts.

Oesophagus: This is the tube that lets food move from the mouth to the stomach.

Stomach: In the stomach food is mixed up and turned into a liquid where it becomes ready for digestion.

Small intestine: This is where all the nutrients from the food are absorbed into the blood and carried to the rest of the body to give you energy and help you grow.

Large intestine: The large intestine brings all the unwanted waste, from the intestine to the rectum where it is passed out of the anus as stool. The rectum is the last few centimetres of the colon just before the anus.



ULCERATIVE COLITIS (UC)

UC affects the rectum and the large intestine (colon). Inflammation and many tiny ulcers develop on the inside lining of the colon resulting in diarrhoea, which occasionally may contain blood. Inflammation causes crampy tummy pain and a feeling that you need to rush to use the bathroom (urgency). If the inflammation is only in the rectum it is called proctitis.

Symptoms may include:

- **Diarrhoea** - Frequent passage of loose stools (poo) with blood or mucous. You may have to use the toilet suddenly or without warning (urgency). You may make several trips to the bathroom in close succession - once you leave the bathroom you may feel the need to go again and could go several times in a short space of time, passing only small amounts of stool each time - this is known as clustering.
- **Abdominal Pain** - can be crampy in nature and before or after going to the toilet
- **Fatigue** - low/reduced energy
- **Weight loss and poor Growth**
- **Anaemia** - when you feel tired and/or weak because the number of healthy red blood cells in your body is too low) due to inflammation and/or blood loss in stools

CROHN'S DISEASE (CD)

CD causes inflammation in the gastrointestinal tract. It can affect any part of the gastrointestinal tract, from the mouth to the anus. Different parts can be affected at different times. It causes inflammation, deep ulcers and may cause scarring to the wall of the intestine.

Symptoms of Crohn's disease may include:

- Diarrhoea
- Weight loss
- Poor growth
- Abdominal pain
- Poor appetite
- Lethargy
- Mouth ulcers
- Perianal ulcers

Complications of CD include:

Abnormal and often uncomfortable skin issues (abscess, strictures, skin tags) around the anus, delays in puberty, infrequency or no periods in girls.

UC and CD are sometimes associated with other inflammatory conditions affecting the joints and skin, eyes and liver.

Inflammatory bowel disease (IBD) is NOT:

- ✗ The same as Irritable Bowel Syndrome (IBS)
- ✗ Infectious or contagious
- ✗ Caused by stress
- ✗ A short term illness
- ✗ It is not fatal

WHAT CAUSES IBD?

The actual cause of IBD is not known. Doctors and scientists worldwide are actively working to find the possible causes, develop new treatments and maybe even one day find a cure. Current research tells us that it is caused by a combination of factors.

IBD is an auto-immune disease. Inflammation is part of the body's normal defence system but in IBD this response is more active.

Genetics: some people may have genes in their bodies that increase the chances of getting IBD.

Environment: Your environment may be anything that your body comes in contact with. Important environmental factors in relation to IBD are infections, smoking, pollution and types of bacteria that live in our intestine.

Recent research has improved our understanding of why people develop IBD and it is clear that for the disease to develop multiple factors must coincide. There is ongoing research into IBD here in Children's Health Ireland at Crumlin and patients are encouraged to participate.



TEST THAT WILL BE CARRIED OUT PRIOR TO DIAGNOSIS.

A number of different tests may be done to find out if you have IBD and to try to identify whether you have CD or UC. During other visits, the doctor may do further tests to ensure that we are treating your disease correctly.

- **Blood tests:** By taking a small sample of your blood we can get a lot of information as to how active your disease is and whether treatments are working.
- **Full blood count (FBC):** This shows if you have developed a:
 - Low red blood cell count (anaemia) from blood loss in your stools.
 - High white cell count, which is a sign of inflammation or infection.
- **Urea and electrolytes (U&E):** This measures the amount of minerals in your blood, which can become imbalanced as a result of diarrhoea.
- **CRP/ ESR:** These are tests of inflammation levels in the blood. They are useful measurements when your disease is more active.
- **Albumin:** A low albumin may indicate that your body is losing protein as a result of bowel inflammation.
- **Varicella/MMR level:** This checks if you have immunity to chicken pox, measles, mumps and rubella as it is important for us to know this before we can start certain medications.
- **TPMT:** This blood test checks if you have a special enzyme in your body that can safely break down certain medicines.
- **Mantoux and QuantiFERON:** These tests are carried out to check your immunity or exposure to tuberculosis (TB).
- **Stool samples:** It may be necessary from time to time to collect a sample of your stool to check:
 - For certain infections that may cause similar symptoms to that of IBD.
 - For your levels of calprotectin to measure inflammation.

- **Upper and lower endoscopy:** To confirm your IBD diagnosis you will need to have an endoscopy, a procedure where the inside of your body is examined internally using an endoscope, a long flexible tube with a small camera at the end.

Both upper (stomach) and lower (colon) endoscopies will be carried out. Once you are asleep the endoscope is passed into your stomach or into the bowel (colonoscopy) to allow the doctor examine the inside of your intestines.

This is not an operation, but an endoscopy can be uncomfortable, so for children/adolescents this procedure is done under general anaesthesia (GA).

Special preparation is needed before colonoscopy, to ensure the bowel is empty so that the gastroenterologist is able to see the lining of the bowel and take biopsies (tissue samples) if needed.

You will be given a diet sheet and instructions before this procedure. You will have to be fasting before this procedure as your stomach must be empty before a GA and to get a clear view of the stomach and colon.

A biopsy is a small piece of tissue, in this case of the surface of the lining of the gut, it is about the size of a half grain of rice. These biopsies are looked at under the microscope and then the diagnosis of UC or CD can be made.

OTHER TESTS

Magnetic Resonance Imaging (MRI)

MRI is used to see parts of the bowel that the colonoscope cannot reach.

MRI uses powerful magnets to send radio waves through the body to take hundreds of cross-sectional pictures. A computer then puts the pictures together to form whole images of internal organs. In IBD it is sometimes used to look for fistulas around the anus.

More specifically a Magnetic Resonance Enterography (MRE) is performed in IBD.

It is a special type of resonance imaging (MRI), performed using contrast material to produce detailed images of the small intestine and bowel. It is particularly useful in working out if Crohn's Disease is in the small bowel and if there are any complications, such as bowel narrowing. Some patients are given a special drink before the scan. The MRI scanner can be noisy, and looks like a tunnel.



Barium Studies

A 'barium meal and follow through' will be done if required however, an MRI scan is the preferred option to assess the patient's small bowel. This test is done in the X-ray (radiology) department. You will have to fast before the test is done so that your stomach is empty. When in the X-ray department you will have to drink a dye called barium, which is a thick white chalky substance. When it is going down through the stomach and intestines the radiologist will take several X-ray photographs. Any areas that may be inflamed will be seen as the barium is going through and will allow the doctors to locate the areas affected by the disease. This test doesn't hurt, but it can take several hours so bring some reading material, music or a computer tablet with you to pass the time).

Capsule Endoscopy

Capsule endoscopy is a way to record images of the digestive tract. The capsule is the size and shape of a pill and contains a tiny camera. After a patient swallows the capsule, it takes pictures of the inside of the gastrointestinal tract. The primary use of capsule endoscopy is to examine areas of the small intestine that cannot be seen by other types of endoscopy such as colonoscopy. These pictures are sent to a small recording device you have to wear on your body. Your doctor will be able to view these pictures at a later time and might be able to provide you with useful information regarding your small intestine. This test is not commonly used in children or adolescents.

Computerized Tomography (CT)

CT, also called a CAT scan, is a procedure that takes hundreds of cross-sectional X-rays in a few seconds. Like putting together a loaf of bread from its many slices, a computer puts cross-sectional X-ray pictures together to form images of the colon, which are then interpreted by a trained radiologist. The scanner looks like a large metal doughnut, and the person being scanned lies on a moving table which slowly slides through the scanner. The process can take between 20 and 45 minutes.

Dexa scan

This is a special scan used to measure bone density. Its purpose is to see whether bone density is normal, or if it is weak and reduced to a level where fractures (breakages) are more likely to occur.

DEXA scans are not available in all children's hospitals so you may be asked to attend an adult hospital to have one.

*Patients will not need all of the above tests. Your gastroenterologist/nurse specialist will discuss which test each patient requires.

TREATMENTS IN ULCERATIVE COLITIS (UC) AND CROHN'S (CD)

Once you are diagnosed with IBD, an individual treatment plan is put together that will address your specific disease needs and is tailored to whether you have UC or CD.

Treating IBD aims to make you feel better, reduce your symptoms, and let you live as normal a normal life as possible.

Treatment involves two parts: Firstly, remission of the disease needs to be induced and secondly, remission maintained. Remission means the inflammation has reduced and healing of the mucosa has occurred, which is determined by the patient's symptoms and blood/stool tests.

IBD treatments can be divided into three main areas: Nutrition and diet, drug treatments, and surgery.



Nutrition and Diet

Exclusive Enteral Nutrition (EEN)

One of the most effective nutritional treatments to induce remission of CD is EEN. This treatment is not used for UC but has been proven to be very effective for CD.

In this treatment, you stop your intake (eating) of all normal foods and drinks for a set period of time and special supplemental drinks are taken instead. You need to drink enough supplements to make sure you are not hungry, can put on weight and help control your symptoms. The dietitian will meet you and answer any questions you might have about this treatment and help you plan how to do it. Usually you will be able to start this treatment as an outpatient without having to come into stay in the hospital.

How does EEN work?

There are three main reasons why this treatment works:

- It gives you all the nutrients you need - this is especially important if you have lost weight or have had a poor appetite.
- It also gives your gut/bowel a rest, allowing it to heal.
- It alters the type of bacteria in your gut/bowel and this can help reduce your symptoms.

If EEN is working for you, you normally continue on it for eight weeks. Your dietitian and clinical nurse specialist (CNS) will link in with you regularly to check on your progress on EEN, and this often involves an outpatient review in the hospital.

If EEN treatment works for you then you should gain weight, have more energy and your symptoms will improve. At the end of the eight weeks, foods are gradually reintroduced and the number of supplements is reduced. Usually it is a good idea to continue taking one-to-two supplements daily to help you stay well.

Naso-gastric tube (NG)

Sometimes if you are not able to drink the supplements, then it can be given through a naso-gastric tube (NG). An NG tube is a very narrow tube that goes down your nose and into your stomach. A supplemental feed is connected to the tube and is given into your stomach overnight while you are asleep. A special pump regulates the amount of feed given. You need to come into hospital for three-to-five days to learn how to do this. After this you can continue it at home and go back to school and your usual activities.



Medical (drug) treatments

STEROIDS

Oral steroids

Steroids are often the first drugs used for the treatment for UC, especially if the symptoms are moderate to severe. These steroids are not like those taken by bodybuilders but are more like those that are naturally found in the body. Usually, we use a steroid called prednisolone. Other steroids that are sometimes used are hydrocortisone and budesonide.

Steroids work by reducing the inflammation of the bowel lining. At first, a high dose of prednisolone is used for two-to-four weeks and then the dosage is reduced or 'weaned down' gradually over the next few weeks until the course of tablets is finished. This slow reduction allows your own body the start making its own natural steroids by the time the steroid tablets are finished.

Intravenous steroids

Occasionally if the symptoms and disease are more severe it may be necessary to give the steroids through one of your veins via an infusion in hospital. This ensures that the symptoms are brought under control rapidly. This infusion is usually every day for at least three-to-five days, after which time you would go back on oral steroids, which will be reduced according to your gastroenterologist's instructions. The oral form of the steroid is then given and continued at a high dose for four weeks, and weaned down according to the directions of your doctor.

Steroid suppositories and enemas

Occasionally if the disease is in the lower part of the bowel or rectum we can use enemas or suppositories to get the disease under control. In other words, the medicine is placed directly in through your bottom. This can be very effective as the drug works directly on the site of inflammation. As a result, unwanted side effects are not usually a problem. However not everyone is comfortable with this form of treatment and we always discuss this treatment with you and answer any questions you have before starting it.

Steroid side-effects

These usually only occur if a high dose of steroids is taken for a long period of time.

The doctor usually prescribes the lowest effective dose for the shortest period of time.

Even though getting these side effects, weight gain, acne and a round appearance to the face may be a little tough, when you stop the steroids these effects will disappear and you will be feeling a lot better. Sometimes steroids which have fewer side effects, such as budesonide, may be used.

Some people may experience hyperactivity, anxiety, low mood and poor sleeping while on steroids. It is best to take your steroid with or after food and in the morning to reduce these side effects.

One of the most important things about taking steroids is that you should never stop taking them suddenly. When steroids are taken for more than a few weeks, the body becomes used to the tablets and begins to make less of its own natural steroids.

If prednisolone is stopped too quickly, the body does not have time to adjust, and dangerous side effects or 'withdrawal symptoms' can occur, which can last until your body resumes making natural steroids over a few weeks. Examples of these symptoms are weakness, tiredness, feeling sick, vomiting, diarrhoea, abdominal pain, low blood sugar, and low blood pressure, which can cause dizziness, fainting or collapse.

You should always seek medical advice if you are unable to tolerate your prescribed dose of steroids. Even when you are finished your steroid course it is important to mention that you have taken a course of steroids to your doctor or dentist as you may need some extra steroid cover if you are undergoing any medical procedures. The dose of steroids may need to be increased for a short time if you are unwell or develop other conditions. This is because the body needs more steroids during physical stress.

AMINOSALICYLATES (5ASA)

These anti-inflammatory drugs include mesalazine (Asacol[®], Pentasa[®], Salofalk[®], Mezavant[®]), olsalazine (Dipentum[®]) and sulphasalazine (Salazopyrin[®]). They are all similar and your doctor will prescribe one that most suits your needs. These drugs work by reducing inflammation of the bowel lining. Aminosalicylates can control the inflammation in IBD very well but they are not as strong as steroids. For this reason, steroids usually are used for the treatment of moderate to severe disease. Often the doctor will start you on both steroids and an aminosalicylate drug so that when you are finished your course of steroids, then the beneficial effect of the aminosalicylates will continue. These drugs can be taken for a long period of time and do not cause the same side effects as the steroids.

ANTIBIOTICS

Antibiotics are sometimes used for treating IBD. They work by reducing intestinal bacteria and possibly by directly affecting the intestine's immune system. Two of the most commonly used antibiotics in IBD are metronidazole and ciprofloxacin.



- **Metronidazole** (Flagyl[®]) can be effective in managing perianal Crohn's (disease involving the bottom area). Side effects of metronidazole may include nausea, headache, and loss of appetite. This drug can also affect the breakdown of alcohol; patients should avoid alcoholic beverages while on metronidazole. Some people get a metallic taste in their mouth from metronidazole.
- **Ciprofloxacin** is another antibiotic that is occasionally used to treat active CD. It is helpful in perianal disease and helps to heal fistulas (abnormal tunnels between two loops of intestine, or between the intestine and another structure, such as the skin).
- **Vancomycin** This antibiotic is used occasionally in people with UC. It is used sparingly as it can lead to bacteria resistance but in the right patient can be very effective. It is taken by mouth.
- **Clindamycin** This antibiotic is also used to treat a wide variety of bacterial infections.

IMMUNOMODULATORS

Azathioprine/6 Mercaptopurine

The body's immune system is responsible for dealing with injury or infections. Inflammation is part of the body's normal defence system but in IBD this response is more active. Oral immunomodulator medicines, such as azathioprine (Imuran®) and 6-mercaptopurine '6-MP' (Purinethol®) have a very important role in the treatment of IBD. It is believed that these drugs help modify the body's immune system, which in turn decreases inflammation, reduces the frequency and severity of relapses and promotes healing.

Your gastroenterologist will consider using immunomodulators if you:

- Have disease that does not respond sufficiently to treatment with aminosalicylates, antibiotics, steroids or EEN.
- Have had repeated course of steroids/EEN.
- Have disease affecting many areas of the intestinal tract.
- Have perianal disease that does not respond to antibiotics.
- Have fistulas.

Once you start taking immunomodulators it is necessary to monitor your blood count levels, weekly initially, then monthly and eventually every three months. It takes time for these drugs to become effective (up to four months), therefore you may be prescribed a course of steroids/EEN at the same time so that by the time the EEN/steroids are finished the immunomodulator has become effective.

Your GP can take and monitor your bloods - your CNS will discuss this with you.

Methotrexate

Methotrexate is another drug that is used as an immunomodulator in the treatment of IBD, to induce and maintain remission of CD. It is used in patients who are EEN/steroid dependent or who have not been able to tolerate azathioprine or 6-Mercaptopurine. It is given by injection or sometimes by mouth once a week (preferably on the same day each week).

To reduce the risk of side effects from methotrexate it may be necessary to take a vitamin supplement called folic acid once a week. You should NOT take this on the same day as methotrexate but three days after. Nausea and vomiting are the most common side-effects of this drug and your doctor may prescribe an anti-nausea drug that can be taken one hour before the weekly methotrexate where necessary.

Blood monitoring is also required if you take methotrexate.

Written information will be given to you before starting any of the above immunomodulating drugs.

BIOLOGICS

Depending on how severe your disease is, your doctor may decide to prescribe biological medicines as part of your treatment plan. Biologics work differently to the other IBD treatments such as EEN, steroids, 5ASA and immunomodulators. Biological drugs are made from proteins and other substances which occur naturally and are made from living cells rather than a chemical process.

There are several different biological drugs used in IBD.

The two most commonly used are:

- **Infliximab** (Remicade® and the biosimilar brands Inflectra®, Flixabi® and Remsima®)
- **Adalimumab** (Humira®)

These biologics are referred to as 'anti-TNF drugs' because they work by targeting a protein in the body called TNF alpha. This protein is found in everyone's blood as part of the body's response to infection. However, in people with IBD, too much TNF alpha is produced, and this causes excessive inflammation. Biological drugs such as infliximab and adalimumab block the action of TNF alpha, and as a result reduce inflammation.

Infliximab is given in the hospital on the day ward and infused via an intravenous drip. There are two parts to the dosing schedule, induction and maintenance. Induction means you will receive three infusions over a short period of time usually over a number of weeks such as week 0, 2, and 6. If the drug works for you further infusions are given every 6-8 weeks to keep your disease under control.

Adalimumab is given as a subcutaneous injection every fortnight at home. You will receive at home training for the administration of this drug.

If you are already on immunomodulators your doctor will discuss with you whether or not to continue these medications once you start your biologic.

Others biologic drugs are;

Golimumab (Simponi®)

Vedolizumab (Entyvio®)

Ustekinumab (Stelara®)

These other biologics are not currently licensed in paediatric patients but may be used in exceptional circumstances.

Detailed information about these drugs will be given to you before you commence treatment.

What is a biosimilar drug?

Biosimilar medicines are essentially copies of existing biologic medicines.

All drugs when first made by pharmaceutical companies are subject to a patent, which means the inventor of the drug has exclusive rights to that drug; however, that patent only lasts for a period of time. After that period of time other pharmaceutical companies can produce the same drug.

Biosimilar medications do not have many of the costs associated with developing a new product and are therefore less expensive.

In order for a biosimilar drug to be approved it must meet very strict standards and prove it is as effective and safe as the original biologic drug. For example, biosimilar infliximab has been shown to be as safe and effective as the originator drug Remicade®, and the Irish Society of Gastroenterology endorses the use of biosimilar infliximab for IBD.



NUTRITION

Food, Drink and IBD

Young people with IBD often worry about their food intake. You can feel sick and sometimes feel that eating food makes your symptoms worse. This can then result in poor nutrition, poor growth and weight loss. Every time you come to the clinic your weight and height are checked and recorded. This helps us to see if you are growing. If you are losing weight or not growing, you will be referred to the dietitian for advice.

Nutrition treatments aim to improve your nutrition and wellbeing, and also to reduce the inflammation in the intestine in the same way as medicines can.

When you are diagnosed with IBD many people try to change their diet to control their symptoms. For most people with IBD we recommend you continue on a normal balanced intake. This will help make sure you get all the nutrients you need to grow and to stay well. Some 'diets' advise you to avoid lots of different foods, but these are not suitable for young people as you will miss out on many nutrients. Sometimes it can help to keep a record of foods eaten to see if a particular food is making your symptoms worse.

Often you may need advice on eating well during busy school days and on ways to improve your diet. You may need extra help to increase your weight so supplemental drinks may be used. If you are missing out on particular nutrients, a medicine may be prescribed, such as calcium, iron or vitamin D.

You should always continue the medications you have been prescribed. Some medicines such as steroids can affect your appetite so ask to speak to the dietician if you are concerned or have any questions.

What are supplemental drinks?

Supplemental drinks are useful to boost your daily intake, especially if you have not been eating well. They are milk based or juice based and available in different flavours and sizes.

They contain extra protein, calories, vitamins and minerals so they provide missing nutrients and can help you to put on weight if needed.



SURGERY

UC

Sometimes in patients with UC, surgery may need to be considered. This is usually necessary if the disease does not respond to drug therapy or such treatment results in severe side-effects. It may also be considered if there is a sudden severe deterioration of symptoms where there is a danger of bowel perforation. Surgery usually involves removing the colon, which results in the formation of a temporary ileostomy (stool draining into a special type of bag).

CROHN'S

Surgery in Crohn's Disease is less common and may be necessary to:

- Remove part of the small or large bowel that is most diseased
- Remove narrowed sections of bowel (strictures)
- Drain abscesses

Although the idea of an operation may be scary, generally people who have had IBD surgery are glad they had it done as they feel so much better. The decision to have an operation will only happen if it is necessary for you and following a lot of discussion with you and your family.

Surgery usually improves the quality of life of those that require it as they typically have been unwell for some time prior to the surgery. It is often necessary to keep taking your medicines after surgery.

FREQUENTLY ASKED QUESTIONS (FAQs)

DO MANY CHILDREN HAVE IBD?

In recent years there has been a dramatic increase in the amount of children diagnosed with IBD. Approximately 100 children every year will be diagnosed with IBD in Ireland. Currently over 400 patients attend the IBD service at Children's Health Ireland at Crumlin.

The increase is consistent globally and the cause of this increase is still unknown. Research is ongoing.

WHO WILL HELP ME TO GET BETTER?

Your care will be managed by a team of specialist health professionals, primarily by a gastroenterologist, CNSs, doctors in training, dietitians, and other healthcare professionals as needed.

Doctors: The gastroenterologists are among the first people you will meet when you have been diagnosed with IBD and they will explain to you the nature of the disease and the treatment options available. They will also meet you at all your clinic visits to the hospital and will be able to assess if the treatments that you are on are working effectively or not.

IBD Clinical Nurse Specialist (CNS): The IBD CNS works very closely with the medical team and will also be present on the day of diagnosis. They will help explain the nature of illness to you and how all the treatment options will help to make you feel better. They are available as a 'link' person and advocate between you and the medical team so you will be able to phone her/him if you are worried about anything or if you do not feel well.

They will liaise with the team of doctors and where possible sort the problem out over the phone. They will also arrange for you to be seen in outpatients. It is your responsibility to liaise with your CNS if you are unwell or have questions/concerns about your IBD.

Biologics CNS: These specially trained nurses are available as a 'link' person and advocate between you and the medical team so you will be able to phone her/him if you are worried about anything or if you do not feel well. They are available to coordinate, educate and plan your care when you are receiving treatment with biologic drugs. If dates of infusions are not suitable for a variety of reasons the biologics CNS is happy to change dates, etc, if adequate notice is given.



Dietitian: The dietitian is probably your most valuable link to successful CD treatment after initial diagnosis. They will guide you through the process and liaise with the rest of the team re progress. For all patients, they will also offer you advice on healthy eating and help make sure that you are a healthy weight. She/he will also offer advice on supplements if they feel that this is necessary and will suggest food that may help you feel better. You can be referred to the dietitian if you have any queries about your diet.

Psychologist: The psychologist is available to all children diagnosed with IBD. The psychologist is there to help you to get used to living with IBD and can offer support with ways to cope with the disease.

Social worker: The social worker is available to provide psycho-social support to parents and children with IBD.

Pharmacist: The hospital pharmacist is responsible for ensuring that the correct medicines are prescribed for you. The pharmacist advises on selection of medicines, provides education and advice to patients and parents about their medications and monitors the effects of treatments to ensure that they are safe and effective. The pharmacist can also deal with shared care hospitals, GP practices and community pharmacies to ensure you get your medicines locally.

Researchers: The IBD team are very active in the area of research and are involved in many studies related to the incidence and management of IBD. At diagnosis we actively encourage any patients to help us with this research, as the key aim of research is to improve care and outcomes for all patients. The team will speak to you at diagnosis and let you know what is involved. Participation is entirely voluntary, so it is your choice if you want to be involved with any research.

WHAT HAPPENS WHEN I ATTEND THE HOSPITAL?

You will attend the hospital for clinic appointments, nurse specialist appointments, MDT appointments (medical social worker, dietitian, psychology etc.), and procedures (endoscopy, MRI, blood testing etc.) and transition clinics.

Clinics adopt a child-family centred approach to empower both parents and children to manage and cope with their IBD. Children and teenagers are always included in clinic visits and all information relating to their care is discussed with both the child and their parents.

Your clinic visits here in Children’s Health Ireland at Crumlin will be in the medical tower 2 of the hospital unless stated otherwise on your clinic letter. When you check in for your appointment, you will meet the clinic nurse who will perform your height and weight. You will be instructed to proceed for bloods/tests if they are required. You will then see the doctors and CNSs.

It is advisable to bring some snacks and toys/books/entertainment for your clinic appointment as delays can be expected and unavoidable.

**BEFORE YOU LEAVE THE HOSPITAL ON YOUR CLINIC DAY
PLEASE ENSURE THAT YOUR GUARDIAN/PARENT HAS:**

- ✓ *Booked a return appointment for your next visit.*
- ✓ *Requested a repeat prescription if necessary.*

Where possible, appointments are coordinated to reduce the number of trips to the hospital but this is not always possible.

If you cannot attend your appointment, it is important to call the outpatients department as soon as you/your guardian can to let us know and so we can reschedule your appointment.

If you are attending for a day case, you will be attending the medical day ward or surgical day ward. Please read all your/your child’s appointment letters correctly and check in at admissions before you proceed to the day wards. If you/your child has been in a hospital facility outside the Republic of Ireland, for any reason, you must inform your CNS as soon as possible. Your/your child’s procedure may be cancelled if this information is not given in enough time prior to a procedure for infection control reasons.

If you are attending for x-ray, ultrasound, CT or MRI you will be attending the x-ray department. Please read all your/your child’s x-ray appointment letters and instructions carefully. You/your child may need to fast prior to your appointment. Please check if you/your child is required to stop any medications prior to your visit also.

WHAT HAPPENS IF I AM UNWELL?

IBD symptoms are usually gradual and increase over days to weeks in which case you should liaise with your CNS if you feel you have IBD symptoms.

You should attend your out-of-hour's doctor or emergency department if you are experiencing:

- Fevers (temperature >38.5 degrees)
- Sudden/ongoing vomiting
- Sudden/ongoing abdominal pain
- Signs of dehydration (dry lips, decrease urine output, large volumes of vomiting/diarrhoea)
- Headaches/dizziness

If you are unwell from non IBD related illness please contact your GP in the first instance.

WHAT HAPPENS IF I AM UNWELL OUT OF HOURS?

If you are unwell out-of-hours, you should attend your GP, an out-of-hour's doctor on call service, or the emergency department.

It is very important to know the name of your condition, all of your medications and be able to give a good accurate history of your symptoms when attending an out of hour's service.

Once clinically assessed by an out-of-hours doctor they can contact the gastroenterology team in Children's Health Ireland at Crumlin for advice on how best to treat you.

WHAT EFFECT WILL IBD HAVE ON MY SCHOOLING, SPORTS AND LEISURE ACTIVITIES?

When well, you should be able to lead a normal life and enjoy all the activities that your friends enjoy however if your disease is active you may tire easily and not be as active as you would like.

You may find that when you are experiencing a flare you may have to rest more often and take some time off school and college. It may also help to rest from physical exertion so don't feel guilty for taking a break.

CAN I GO ON HOLIDAYS?

You should be fine to go on holidays as normal, especially with the correct planning and preparation. When travelling, make sure that you have your medication in your hand luggage in case your bags get mislaid. The hospital can provide a letter for the airline to allow you carry your medications and medical supplies on board with you. You should also bring an extra supply of the medication, in case of delays. It is also a good idea to take a European Health Insurance Card (EHIC), which is available online, in addition to travel insurance and a copy of your prescription. While on holidays if you become unwell you should contact the nearest medical centre and if necessary they may make contact with the hospital where you are normally treated.

If you are eating out make sure to eat food that is well cooked and drink only bottled water when abroad. Avoid ice in drinks, as sometimes poor-quality water is used to make the ice.

If you get diarrhoea it may be normal due to change of diet. But if symptoms worsen, contact the local doctor.

It is essential that you wear a factor 50+ sun cream with UVA and UVB protection when in the sun especially if you are taking immunomodulating drugs.



WHAT SHOULD I TELL PEOPLE?

It is important to know that having IBD is not your fault and is not a result of anything that you have done in the past. Everyone is different and therefore it is not essential that you tell people that you have IBD, however you may find it very helpful to tell some of your close friends that you have been diagnosed with IBD. That way it is easier for them to understand that at times you may be feeling unwell, need to rest or use the bathroom more often and take regular medications. A lot of children with IBD have said that telling their friends has been very helpful and that their friends have been very supportive. You don't have to tell people every single detail. Sometimes it's enough to say that you have 'tummy trouble' and need to attend the hospital to keep it under control.

Some people around you including your family, friends or teacher may become overprotective when they know you have IBD, so it is important that you explain to them that you can partake in all the activities that they are doing and that you will let them know if you feel unable to join them in certain activities. We can provide written information for your school if necessary.

ACCESSING PSYCHOLOGY SERVICES

When you or your child is unwell and receives a diagnosis of IBD, it is natural to feel worried and stressed. Following diagnosis and when starting treatment, you may find that you or your child experience a range of different emotions; relief, shock, sadness or anger. You or your child may question "why me?" or "Why my child?", "We've done nothing wrong" or "we don't deserve this". All these thoughts and feelings are normal, they may come and go, range in intensity and/or change over time. There is no right or wrong way to feel following a diagnosis of IBD.

Acknowledging these thoughts and feelings and accepting them as how you think and feel at this particular time, can help you and your child adjust to their new diagnosis and treatment.

The medical environment may be new and unfamiliar to you and your child therefore you both may feel, anxious and/or overwhelmed. As you and your child become more familiar with the hospital setting and procedures, you will begin to feel less anxious and more confident about managing IBD.

Adjustment is a process which takes time. Be gentle with yourself during the adjustment phase. Returning to the regular daily routines, e.g., work, school, activities (as soon as medically possible) and engaging with natural supports, e.g., family and friends can help you and your child adjust well to IBD.

The diagnosis of a medical condition is naturally a stressful event and it therefore takes time to adjust. If you or your child are experiencing persistent difficulties and would like to meet with the team psychologist, please mention this to your consultant or CNS. Engaging with all members of the IBD, multidisciplinary team, can help you and your child live well with IBD.

TRANSITIONING TO ADULT CARE

‘Transition’ means that you will be moving from the paediatric IBD service to be looked after by a team who specialise in caring for adults with a long-term illness. Transition is the planned move of your care to an adult healthcare provider. Transition is a step necessary to achieve the best outcomes possible for patients and their families in areas of health, independence and adulthood. Transition can be defined as ‘a purposeful, planned process that addresses the medical, psychosocial and educational/vocational needs of adolescents and young adults with chronic physical and medical conditions as they move from child-centred to adult-orientated healthcare systems’ (Blum et al, 1993, cited by DH/Child Health and Maternity Services, 2006).

Transition from Children’s Health Ireland at Crumlin usually happens when the patient is in their 16th year and ideally when they are in transition year in secondary school. We are very fortunate in Ireland to have excellent adult gastroenterologists specialising in IBD throughout the country. Almost all of these gastroenterologists have a CNS working with them so you will continue to have a nurse contact person in your adult centre. We aim to provide a seamless transition where possible with our transition clinic where the adult group come to Crumlin for the initial visit and then the CNS from Crumlin are present on the first visit to the adult clinic visit. We also try as much as possible to transfer care to a centre near home or a college that you hope to attend.

Part of the transition preparation will include you becoming more involved in managing your healthcare and achieving more independence. You will need to find out all about your medical history and your condition. You will become more involved in looking after your medications, treatments, tests and procedures. Knowing how to keep well and manage your condition through attendance at clinic appointments, a good diet, exercise routines and other lifestyle choices is also part of the transition process.

Transition is a planned, phased process, and these phases are introduced in early adolescence, with the young person becoming aware of their own health and care needs, and the full implications of their medical condition. As transition date approaches, some of the clinic visits will involve the patient being seen independently without their parent or guardian in the room. This is to determine if the patient is happy and ready for transition and has adequate knowledge of their disease and treatment options. This should not be viewed as a test but an opportunity to take responsibility for their disease and treatment.

In an adult outpatient clinic, the patient is treated as an adult and will be expected to know about his/her disease and medication. Management of the disease will be discussed with you directly and if you have any concerns you are advised to discuss them at clinic.

One concern about moving to adult services is in regard to colonoscopies. In Crumlin all children having a colonoscopy have a general anaesthetic. In adult services you are given sedation, you would not be awake for the procedure and most people have no memory of it. The adult team will be more than happy to take the time to give any necessary explanation prior to any planned procedure that you will be undergoing.



Some useful supports include

Barrettstown

All children who attend the IBD service are eligible to attend Barrettstown serious fun camps in Co Kildare.

These free camps are highly recommended for all children and their families who have a diagnosis of IBD. The excellent activity leadership and unobtrusive medical supervision that can be offered at these camps help children to forget about their illnesses, learn to have fun and rebuild their confidence and self-esteem.

For more information please visit their website www.barrettstown.org



Useful Websites

Children's Health Ireland (CHI) at Crumlin: www.olchc.ie

The Irish Society for Colitis and Crohn's Disease (ISCC): <https://iscc.ie>

HSE information on IBD: www.hse.ie/eng/health/az/i/inflammatory-bowel-disease/

Crohn's and Colitis UK: <https://www.crohnsandcolitis.org.uk>

European Federation of Crohn's & Ulcerative Colitis Associations (EFCCA):
www.efcca.org

American Crohn's & Colitis Foundation: www.crohnscolitisfoundation.org



Recommended Book

Your Child with Inflammatory Bowel Disease: A family guide for caregiving.

By the North American Society for Pediatric Gastroenterology, Hepatology and Nutrition

GLOSSARY

Acute:	Sudden onset of symptoms.
Anaemia:	Low blood count.
Anus:	The opening of the back passage (bottom).
Barium meal and follow through:	A test that follows the barium through your intestines using X-ray to see any areas of inflammation or narrowing.
Barium:	A chalky substance that can show up the stomach or bowel under x-ray.
Biopsy:	A small part of the bowel that is removed e.g. the large intestine or the stomach)for examination under the microscope for diagnosis.
Colitis:	Inflammation of the colon.
Colon:	The large bowel.
Colonoscopy:	A test where flexible tube with a camera is passed into your bowel when you are under general anaesthetic, to allow the doctor to see inside the gut.
Crohn's:	Inflammation of one of more part of the intestine.
Exclusive Enteral Nutrition:	A special liquid diet containing all the essential nutrients that you need.
Enema:	A liquid medicine inserted into the back passage which is used to treat a specific area of the large bowel. They can also be given prior to a colonoscopy to clear out the bowel.
Fistula:	An abnormal connection, or small sore sometimes found around the anus in people with IBD.
Gastro intestinal tract:	The digestive tract.
IBD:	An umbrella term used for ulcerative uolitis (UC) or Crohn's Disease (CD).
Ileum:	The lowest part of the small intestine.
Immunosuppressant:	A drug used to suppress the immune system and sometimes reduces inflammation.
Inflammation:	Irritation or soreness.
Infusion:	A drug given via a drip into the vein.
Intestine:	Another word for the bowel or gut.
Large bowel:	The lowest part of the intestine. The large bowel is often known as the colon.
Mesalazine:	A drug used to treat IBD. It works by reducing the inflammation of the gut and to keep the disease in remission.
Naso gastric tube:	A special tube that is inserted into the tummy via the nose to give a special liquid diet when food cannot be taken through the mouth.
Nausea:	Feeling sick.
Olsalazine:	Another drug used in IBD to reduce inflammation and keep the disease in remission.
Peri-anal:	Area around the anus.
Radiologist:	A specialist who reads X-ray and barium tests.
Rectum:	The last part of the large bowel just above the anus.
Relapse:	When the disease becomes active and you are not feeling well.
Remission:	When the disease is not active and you feel well.
Steroids:	A drug used to reduce the inflammation of the gut. They have some effects like cause weight gain, acne and a round facial appearance which all disappear when the medications are stopped. The important thing about steroids is that you should not stop taking them suddenly.
Sulphasalazine:	A drug used to reduce the inflammation of the gut lining.
Suppository:	A bullet shaped solid medication that is inserted into the rectum to treat disease low down in the colon.
Ulcer:	A sore part of the intestine that is similar to a cut.
Ulcerative Colitis:	Inflammation of the rectum and colon.
Upper endoscopy:	A test where a flexible tube with a camera is passed into your stomach while you are under general anaesthetic to allow the doctor to see if there is any inflammation.



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