

**CROHN'S &
COLITIS UK**

**FIGHTING
INFLAMMATORY
BOWEL DISEASE
TOGETHER**

IBD IN CHILDREN

A PARENT'S GUIDE



INTRODUCTION

ABOUT THIS BOOKLET

If your child has recently been diagnosed with Crohn's Disease or Ulcerative Colitis, you might have questions about the condition, how it might affect your child and the treatments that may be used. This booklet has been produced to answer some of these questions. It also looks at some of the more general concerns that you may have as a parent, and includes suggestions based on the experiences of other parents of children with Crohn's Disease or Ulcerative Colitis. It has been written mainly for parents of children under 16, but we hope it may also be of interest to parents of older children.

All our publications are research based and produced in consultation with patients, medical advisers and other health or associated professionals. However, they are prepared as general information and are not intended to replace specific advice from your own doctor or any other professional. Crohn's and Colitis UK does not endorse or recommend any products mentioned.

If you would like more information about the sources of evidence on which this booklet is based, or details of any conflicts of interest, or if you have any feedback on our publications, please visit our website.

About Crohn's and Colitis UK

We are a national charity established in 1979. Our aim is to improve life for anyone affected by Inflammatory Bowel Diseases. We have more than 35,000 members and 50 Local Networks throughout the UK. Membership costs from £15 per year with concessionary rates for anyone experiencing financial hardship or on a low income.

This publication is available free of charge, but we would not be able to do this without our supporters and members. Please consider making a donation or becoming a member of Crohn's and Colitis UK. To find out how call **01727 734465** or visit **www.crohnsandcolitis.org.uk**.

CONTENTS

1. IBD in children

Introduction	03
What is Inflammatory Bowel Disease?	03
What are the main symptoms?	06
What causes IBD?	07
Can other parts of the body be affected?	08
Will my child get better?	09

2. Tests and treatments

What tests might my child need?	11
What kinds of treatment are there?	15
How does dietary treatment work?	16
Is a special diet helpful at other times?	18
What drugs are used for IBD?	18
Important points about drug treatment	21
Should my child have vaccinations?	22
When is surgery necessary?	23
Is there a risk of bowel cancer?	25

3. Living with IBD

How can I tell if my child is developing a relapse?	27
Talking with Health Professionals	27
Where can we go for information?	29
How do I come to terms with my child's IBD?	29
How can I help my child cope?	30
Practical tips	32
How can I encourage my child to eat?	32
What can I say to other people about my child's IBD?	33
What is the best way to approach schools and teachers?	34
How can I help my child cope with stress at school?	35
How can I help my child manage tiredness and fatigue?	36
Can we go on holiday with a child with IBD?	37
Is there financial help for parents of child with IBD?	38
What else can I do to help my child?	39

INTRODUCTION

In the UK, one person in 210 has Crohn's Disease or Ulcerative Colitis, conditions collectively known as Inflammatory Bowel Disease or IBD. These illnesses can start in childhood and around a quarter of all people diagnosed with IBD are children or adolescents.

If you have a child with Inflammatory Bowel Disease, it is natural at times to feel isolated and worried about how you will cope, especially when your child is first diagnosed. It may help to bear in mind that:

- while your situation is unique, you are not alone - there are thousands of other parents in a similar situation with similar experiences and concerns.
- nowadays there is a good chance that these conditions can be kept under control. The aim of treatment is to limit the number of times your child's bowel is inflamed, so that he or she can get on with everyday life with as little disruption as possible.

WHAT IS INFLAMMATORY BOWEL DISEASE?

Inflammatory Bowel Disease is the name given to a group of conditions, of which Crohn's Disease and Ulcerative Colitis (UC) are the two main forms. It is not always possible to distinguish between the two, in which case the diagnosis of IBDU (IBD Unclassified) or Indeterminate Colitis may be given.

IBD is not the same as IBS (Irritable Bowel Syndrome). IBS has some symptoms similar to IBD, but is a different condition and is treated differently.

IBD IN CHILDREN

To understand IBD, it can help to know how the digestive system works. As shown in the diagram overleaf, the gastrointestinal (digestive) tract is like a long tube that starts at the mouth and ends at the anus.

When we eat, food passes down the oesophagus and into the stomach, where gastric (digestive) juices break it down into a porridge-like consistency. The partly digested food then moves through the small intestine (also known as the small bowel). Here it is broken down even further so the nutrients (useful parts of food) can be absorbed into the blood stream. The waste products from this process - liquid and undigested parts of food - are then pushed into the colon (also known as the large intestine or large bowel). The colon absorbs the liquid, and the left over waste forms solid stools (faeces). These collect in the last part of the colon and rectum until they are passed out of the body in a bowel movement.

Crohn's Disease and Ulcerative Colitis both cause inflammation of the digestive system. Inflammation is the body's reaction to injury or irritation and can cause redness, swelling and pain. In Crohn's Disease, this inflammation can be anywhere from mouth to anus – but is most common in the small intestine or colon. The areas of inflammation are often patchy, with sections of normal gut in between. Both the lining and the deeper layers of the bowel wall may be affected.

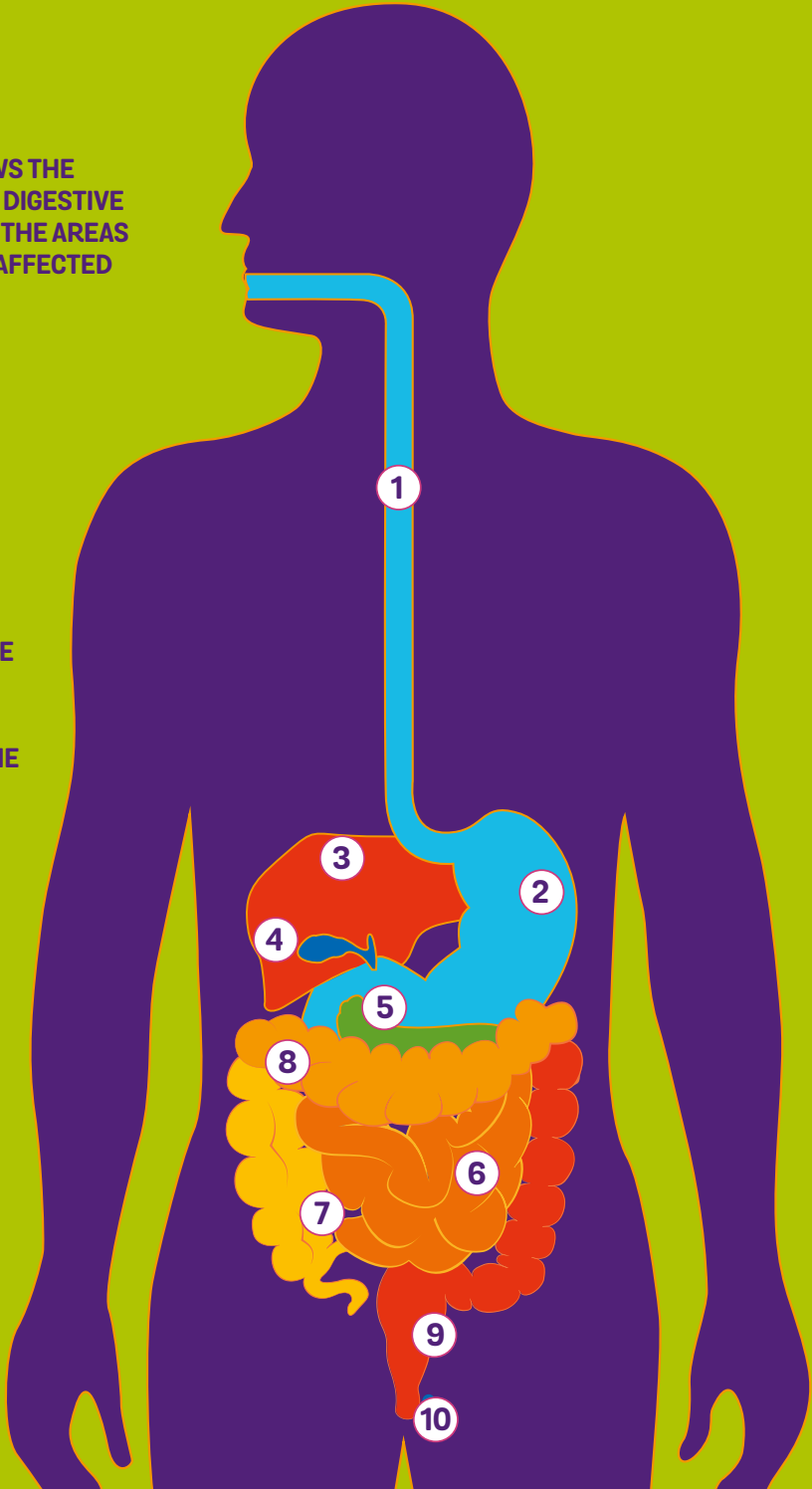
Ulcerative Colitis involves only the colon and rectum (together called the large bowel). In this disease, the inner lining of the large bowel becomes inflamed and tiny ulcers develop on its surface.



THE DIGESTIVE SYSTEM

THE DIAGRAM SHOWS THE MAIN PARTS OF THE DIGESTIVE SYSTEM INCLUDING THE AREAS MOST LIKELY TO BE AFFECTED BY UC OR CROHN'S.

- 1 OESOPHAGUS
- 2 STOMACH
- 3 LIVER
- 4 GALL BLADDER
- 5 PANCREAS
- 6 SMALL INTESTINE
- 7 ILEUM
- 8 LARGE INTESTINE (COLON)
- 9 RECTUM
- 10 ANUS



WHAT CROHN'S DISEASE AND ULCERATIVE COLITIS ARE NOT:

- They are not infectious or contagious.
- They are not the same as Irritable Bowel Syndrome (IBS).
- They are not cancer.

WHAT ARE THE MAIN SYMPTOMS?

“

Albert was pale, tired and had a very sore bottom. He was emptying his bowel a lot, and his poo sometimes had blood and mucus in it. ”

Sarah, mother to **Albert**, age 3, diagnosed with colitis in 2015

Crohn's Disease and Ulcerative Colitis are sometimes described as chronic conditions. This means that they are ongoing and life-long, although your child may have long periods of good health (remission) as well as times when the symptoms are more active (relapses or flare-ups).

With both conditions, symptoms can include

- pain in the stomach or tummy
- diarrhoea (sometimes mixed with blood and mucus)
- loss of appetite, weight loss and slowed growth in height (particularly in Crohn's Disease)
- nausea
- tiredness and fatigue
- feeling generally unwell with raised temperature and fever
- anaemia (a reduced number of red blood cells).

Children with Crohn's Disease may also have a number of symptoms including:

- **Abscesses** – collections of pus that can become swollen and painful. They are often found in the area around the anus and can cause a fever or lead to a fistula.

IBD IN CHILDREN

- **Fistulas** – these are narrow tunnels or passageways between the gut and another organ. In perianal Crohn's (Crohn's in the area around the anus) fistulas often run from the anal canal to the skin around the anus. They appear as small openings in the skin that leak pus or sometimes faecal matter. They can irritate the skin and are often sore and painful. They can usually be treated with medication and/or surgery. Less commonly, fistulas may also occur in children with Ulcerative Colitis, particularly after surgery.

For more details, see our booklets: **Crohn's Disease** and **Ulcerative Colitis**, and our information sheet: **Living with a Fistula**.

WHAT CAUSES IBD?

Although there has been much research, the cause of IBD is still uncertain. Many researchers now believe that IBD is caused by a combination of factors: the genes a person has inherited which may make them more likely to develop IBD, and then an abnormal reaction of the immune system (the body's protection system) to certain matter in the intestines, possibly triggered by something in the environment. Viruses, bacteria (including those that live normally in our intestine), diet and stress have all been suggested as environmental triggers, but there is no definite evidence that any one of these factors is responsible.

Research is continuing, especially into genetic (inherited) factors. It has been found that parents with IBD are slightly more likely to have a child who develops IBD. How likely seems to vary with the condition and is also higher in some population groups. Estimates vary but research suggests that in general, if one parent has UC, the risk of their child developing IBD is about 2%. That is, 2 out of 100

IBD IN CHILDREN

children born to couples where one parent has UC might be expected to develop IBD at some point in their lives. For Crohn's the risk is generally thought to be between 5% and 10% – that is, for every 100 people with Crohn's having a child, 5 to 10 of the children may develop IBD. If both parents have IBD, the risk can rise to above 30%. Even with genetic predisposition – an increased risk because of a person's genes – additional factors are needed to trigger IBD.

Nothing you have done or not done will have caused your child to have IBD.

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CAN OTHER PARTS OF THE BODY BE AFFECTED?

“

There were little signs there for a while before Crohn's Disease was diagnosed. Ellie would have a sore mouth, suffered terribly with her skin as well as having bouts of tummy ache, constipation and diarrhoea. ”

—

Donna, mother to Ellie, age 11, diagnosed with Crohn's Disease in 2012

Some children with IBD develop associated conditions in other parts of the body. The most common one is arthritis (inflammation of the joints). This type of arthritis usually responds well to most of the anti-inflammatory drugs given to treat IBD, and so the arthritis often improves as the IBD improves.

Some children may develop mouth ulcers and thickening of the lips, particularly if they have Crohn's Disease. Directly applied creams or gels, available from your doctor, can usually help heal up the ulcers if they do not improve with the IBD treatment. Mouthwashes may also be helpful.


Skin rashes are quite common, and sometimes come on at the start of a flare-up. One type of rash, erythema nodosum can cause small painful red patches on the shins. These should disappear with the treatment of the IBD.

IBD can occasionally affect the liver. Your child's doctor will be screening for liver problems by doing regular blood tests.

In a small number of children, the eyes may become inflamed. You should speak to an eye specialist or your child's doctor if your child has sore, red or inflamed eyes, as occasionally more serious eye problems can occur.

WILL MY CHILD GET BETTER?

Currently, IBD cannot be cured, in other words taken away completely, but a lot can be done to minimise its effects and help your child live a normal life. Once treatment is started, many of your child's symptoms should improve within a few weeks. Although there may then be periods of relapse when your child might be ill with IBD, there will probably be periods of remission when their symptoms more or less disappear. Most children with IBD can continue to go to school and take part in sports and other interests. Many then go on to further education, training or employment, and successfully have families of their own.





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WHAT TESTS MIGHT MY CHILD NEED?

If your GP suspects that your child has IBD, he or she will be referred for a range of tests, usually at a hospital paediatric (children's) unit with a children's specialist in intestinal diseases. This doctor is called a paediatric gastroenterologist.

Blood tests are usually carried out first. These are done to see if there is any inflammation in the body and if your child is anaemic. Stool (poo) samples will also be tested to exclude infectious diarrhoea - called stool microscopy, culture and sensitivity tests. The doctor might also request a faecal calprotectin or faecal lactoferrin test to detect an increased level of specific proteins in the stools that can be a sign of active inflammation of the intestines.

“

When Albert had the endoscopy, he was very young, so he couldn't really communicate his feelings. But he handled the test and the hospital visits very well.

”

Sarah, mother to **Albert**, age 3, diagnosed with colitis in 2015

Most children then have an endoscopy (a camera test to look inside the bowel). This is done with an endoscope, a long flexible tube (about as thick as your little finger) with a light at the end, linked to a video system. In an upper gastrointestinal (GI) endoscopy (sometimes known as an OGD – oesophago-gastro duodenoscopy), the endoscope is passed through the mouth to look at the oesophagus, the stomach and the top part of the small intestine. In a colonoscopy (an endoscopy of the large intestine) a similar tube is inserted through the anus (bottom) into the colon (large intestine) and into the lower part of the small bowel. These tests allow the specialist to get a clear look at the internal lining of the intestine and to take biopsies (small scrapings of tissue) through the endoscope. These biopsies are then examined under a microscope to help with reaching a diagnosis.

Your child will not be aware of what is happening during the endoscopy. In younger children endoscopies, including colonoscopies, are done under a general anaesthetic. In older children, as an alternative, these tests can be carried out under heavy

sedation given into a vein in the arm. If your child is having a colonoscopy, your IBD team may prescribe a low residue or liquid diet a day or so before the test. Your child will also be asked to take a laxative to clear the bowel before the camera test, and many children find this the most uncomfortable part of the test. Your child may need to take the laxative at home before coming to the hospital, and it can be helpful to talk this through beforehand with the doctor or nursing staff, so you and your child know what to expect.

You will be asked to sign a consent form for your child's endoscopy. If you have any worries or concerns, especially if you have not already talked about the tests with your doctor or specialist, do take this opportunity to ask questions. Many hospitals have an IBD or paediatric gastroenterology nurse specialist whom you can contact for help and support. You may find the hospital or unit has a booklet on endoscopies written especially for children and their parents.

Upper GI endoscopies and colonoscopies cannot tell your doctor about the section of the small intestine the endoscope cannot reach, so other tests may also be needed. This is usually an ultrasound or MRI scan of the abdomen, but may be a barium meal test or capsule endoscopy.

A barium meal and follow through test may occasionally be used. It is a special x-ray that involves drinking a fluid (dye) which shows up the outline of the intestine. It is not painful but it does take a couple of hours for the dye to go through. Some children may have difficulty drinking the large volume of liquid needed. If this happens, the nurse may have to pass a tube through the nose down to the stomach to help. Children having an MRI scan, which uses magnetic imaging to give a picture, will also be asked to drink a liquid before having the test.

“

Ben had various colonoscopies but they were carried out under general anaesthetic so he knew very little of them, and blood tests have become a routine part of life now. ”

Bev, mother to Ben, age 18, diagnosed with Ulcerative Colitis in 2007

A capsule endoscopy may be carried out in a child with IBD. In a capsule endoscopy, your child swallows a capsule about the size of a large jelly bean, which sends back photographs to an external computer as it goes through the gut. Alternatively, the capsule can be placed in the bowel by an endoscope. Capsule endoscopies are not available in all hospitals, and are not used in very young children. They are also not used in children who may have strictures (narrow sections) in their intestine, as can happen with some types of Crohn's Disease.

Your child may have an ultrasound, which uses sound waves to create an image. This is similar to the ultrasound scan commonly used during pregnancy. Some centres offer CT scans (computed tomography). These combine x-rays and a special computer to create images of the inside of the body. This test is used minimally due to the high dose of radiation involved in it.

Your child will usually be able to have these tests done as an out-patient, but each can take most of a day. After endoscopies, it will take a few days before the results of the biopsies are available.

For more information about tests see our leaflet: **Tests and Investigations for IBD.**





WHAT KINDS OF TREATMENT ARE THERE?

IBD affects everyone differently, but the aim of treatment is to make your child feel better, and then to keep their symptoms under control. There are several kinds of treatment for each condition that may be used one after another, or in combination, at the same time.

Crohn's Disease may be treated with specialised liquid diets (also known as nutritional therapy or enteral feeding), drugs, surgery, or a combination. In children with Crohn's, nutritional treatment is often tried first as studies in children have shown that it is as effective as steroids (see drugs used below) and has fewer side effects. It usually involves taking a liquid diet, instead of food, for a number of weeks. The majority of children respond very well to this nutritional treatment, and it can often mean that steroid use can be reduced or even avoided. Your child may then go on to long term medication to help keep their condition under control.

Ulcerative Colitis and IBDU/Indeterminate Colitis are more likely to be treated by drug therapy, although for some children, surgery may be needed. Unlike Crohn's, Ulcerative Colitis cannot be treated with a liquid diet, although supplementary nutritional drinks are occasionally recommended to provide extra energy (calories) for growth.

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HOW DOES DIETARY TREATMENT WORK?

“

There were times that the dietary treatment interfered with special moments, like birthdays and Christmas. But Ellie has taken it all in her stride and she understands that she must do whatever is needed to try to be well again.

”

Donna, mother to **Ellie**, age 11, diagnosed with Crohn's Disease in 2012

“

My son had two courses of Modulen at the beginning of his treatment. He didn't like the taste of it but it worked well getting him into remission. He now has two Modulen drinks a day, alongside a normal diet, to keep his weight up. ”

—

Rachel, mother to **Thomas**, age 12, diagnosed with Crohn's Disease in 2013

Many children with Crohn's Disease will be treated, at least initially, by being put on an exclusive liquid diet. This involves drinking a specially prepared liquid 'food', such as Modulen IBD or Elemental O28, instead of normal food, usually for a period of about 6-8 weeks. These products are easily digested and also provide all the nutrients necessary to replace lost weight and help your child grow properly.

Once prescribed, these specialised diets should be obtainable at your local pharmacy. They usually come in powder form, to be made up into a drink with water. Most are available in several flavours and trial packs may be available. Some brands also come in ready-to-drink cartons.

The drinks should be spread out through the day. If your child has difficulty drinking a sufficient quantity, they may find the diet easier to take through a nasogastric feeding tube (a fine tube passed through the nose down into the stomach). However, it is usually worth trying to find a flavour or type of liquid food that your child is able to drink without the need for a nasogastric tube. Your dietitian or IBD team should be able to help with this. Once in place, a nasogastric tube should not stop your child going to school, college or taking part in all their usual activities, although some children may feel self-conscious about the tube and it may be worth talking to teachers in advance. For more information about how to speak to teachers, see **What is the best way to approach schools and teachers?** The time that the actual feed is given can be organised to suit your child's daily routine, and some of it can be given overnight while your child is asleep.

“

Evie has had a liquid diet taken through a nasogastric tube. Although coping with the tube and the diet in everyday life is hard, the results have been really good for her in terms of getting the Crohn's into remission. ”

—
Ruth, mother to **Evie**, age 11, diagnosed with Crohn's Disease in 2013

Talk with your child before they start on nutritional treatment about what they would prefer to do during family meal times. Some may prefer to do something else rather than sit with the family, but it is important that this is their decision, and they do not feel they are being excluded from normal family life.

Most children soon begin to feel better once on the diet, although the high concentration of nutrients in the feed can sometimes cause nausea or a headache. This can be due to dehydration so make sure your child drinks enough water while on nutritional treatment. They may also be able to have certain other drinks, but check with your doctor or dietitian first. After treatment, foods are gradually re-introduced, generally over several weeks. Your child's IBD team will advise you on how to do this. As a parent, you may worry that it will be difficult for your child not to have solid foods for this length of time. However, try to remain positive because this is usually a very effective treatment.

For some children with Crohn's Disease, supplemental nutritional treatment (taking a liquid diet as well as food) or another period of exclusive enteral feeding may be recommended during follow-up treatment, to improve growth and help keep the condition under control.



IS A SPECIAL DIET HELPFUL AT OTHER TIMES?

There is no evidence that other special foods or extra vitamins are helpful in children with IBD, nor that avoiding specific foods helps everyone. However, if you find that a particular food appears to upset your child, it is sensible to avoid it after consultation with your doctor or dietitian. For example, some children feel better if they avoid spicy food or drinking large amounts of milk. Your IBD team will give advice about a well-balanced and nourishing varied diet. Occasionally, your doctor may prescribe vitamin or mineral supplements, such as vitamin D or iron, if the body stores are low.

Our booklet, **Food and IBD**, gives further information on how food affects IBD and suggestions for healthy eating with UC and Crohn's.

WHAT DRUGS ARE USED FOR IBD?

The drugs used to treat IBD work by stopping the inflammation and reducing the chance of a relapse or flare-up. As with most drugs, there may be some unwanted side effects, but the medicines prescribed for your child will be used very carefully and in the smallest doses needed to give the desired result. Your IBD team will be monitoring your child's health very closely and should be able to explain in more detail how the medication will work. Ask your doctor any questions you may have about your child's treatment. Older children may also find it helpful to talk their treatment through with their IBD team and find out what to expect and how the drugs may affect them.

There are four main types of drugs used for IBD in children, which may be given separately or in combination.

“

Our daughter has been treated with mesalazine for a while. It has worked well for her and she hasn't experienced any side effects. ”

Andrew, father to **Emma**, age 19, diagnosed with IBD Unclassified in 2005

“

On the whole, my son's experiences of drug treatments have been quite positive. He did have some side effects with taking azathioprine, such as being very tired and getting aching joints, but we managed to minimise these symptoms by taking the drug at bedtime. ”

Bev, mother to **Ben**, age 18, diagnosed with Ulcerative Colitis in 2007

- **Aminosalicylates (also known as 5-ASAs)** such as sulfasalazine and mesalazine, are regularly given to treat mild UC and then longer term, to prevent flare-ups. They may need to be taken every day for several years even when your child is well. You may worry about your child taking medication long-term, but it may help to keep your child's condition stable, which is especially important while your child is growing. When the lower part of the colon or the rectum is affected, aminosalicylate enemas or suppositories (medicine that can be inserted into the bowel through the anus) can be used.
- **Corticosteroids**, often called simply 'steroids', such as prednisolone and budesonide, are given to treat flare-ups and often act very quickly to control the discomfort. However, they can also have side effects such as a rapid weight gain and your child's face may temporarily become chubbier. They can also increase appetite and make your child very hungry. In teenagers, acne can get worse. Some children may become irritable or moody, or revert to earlier behaviours, such as temper tantrums, while on steroids. They may also have trouble sleeping. Steroids are also known to affect children's growth, so the IBD team will try to keep the number of times your child needs steroids and the total dose to a minimum. The side effects of steroids usually go as the dose is reduced. Steroid enemas or suppositories may be used – these cause few side effects as less of the drug is absorbed into the body. Corticosteroids are quite different from the anabolic steroids sometimes used by athletes.
- **Immunosuppressants**, such as azathioprine, and mercaptopurine may be started as soon as the diagnosis is known or following a relapse. They may also be used if the condition becomes steroid-dependent (flares up as soon as steroids are

stopped). Immunosuppressants are slow acting and usually take 8-16 weeks before being fully effective. These drugs reduce inflammation by suppressing or dampening down the immune system, and at the beginning of treatment may cause nausea, vomiting and loss of appetite. It is very important that your child has regular blood checks while on this type of medication as it can suppress the production of blood cells in the bone marrow. If this happens, the dose can be adjusted, but sometimes the drug must be stopped.

Other immunosuppressants such as methotrexate, may be used if your child has not responded to, or had troublesome side effects, from azathioprine or mercaptopurine.

- **Biologics**, such as infliximab and adalimumab, are drugs which work with the immune system to block the chemicals that cause ongoing inflammation. These drugs may be used if your child has moderate to severe Crohn's Disease or UC which is not responding to other treatments. Infliximab is given by an intravenous infusion (through a drip in the arm) in hospital, while adalimumab is injected under the skin (subcutaneously) of the tummy or arm, at home.
- **Biosimilars**, such as Inflectra and Remsima, are a new type of biological drug which has become available recently. If your child has been prescribed infliximab, you may come across the term 'biosimilar'. A biosimilar drug is a biological medicine that is developed to be highly similar to an existing biological medicine. For more details, see our information sheet: **Biological Drugs**.

For further details on drugs, see our individual drug treatment sheets.



IMPORTANT POINTS ABOUT DRUG TREATMENT

Taking steroids can affect the production of cortisol, a natural hormone important in stressful situations, and so steroid treatment should be reduced gradually, rather than stopped abruptly, to give the body time to adjust. If your child is on steroids, anyone treating them for another illness or in an emergency, for example, following an accident, will need to know about their steroid treatment. One way to ensure this is for your child to carry a ‘Steroid Card’ (available from pharmacists) or wear an emergency bracelet, such as those obtainable from MedicAlert.

Steroids and immunosuppressants can reduce your child’s ability to fight infections. Some infectious diseases, such as chicken pox, can be serious, so talk with your specialist about what to do if your child comes into contact with someone with such an infection. Immunosuppressants can also increase sensitivity to sunlight and make it even more important for your child to use high factor sunscreen or sunblock.

Whatever IBD medication your child is prescribed, do check with their doctor before you give them any other medicines, as there could be an interaction with the IBD treatment. This includes over the counter medicines and any herbal, complementary or alternative treatments.



SHOULD MY CHILD HAVE VACCINATIONS?

You may wonder if your child can have vaccinations if they are taking certain drug treatments. It is always best to check with your IBD team before your child has any vaccination.

If your child is taking steroids or immunosuppressants, they may have a reduced immune response and may be more open to infection, so should not receive certain live vaccines. These include the MMR (measles, mumps, and rubella), yellow fever and BCG (tuberculosis) vaccines.

It is nevertheless important to keep up-to-date with routine vaccinations, which can be given by your GP or practice nurse. Fortunately, these routine vaccinations can usually be done using inactivated (not live) vaccines, for example, the 3-in-1 (Td/IPV) teenage booster, is given as a single jab and contains inactivated vaccines against diphtheria, tetanus and polio. If your child needs to have a live vaccine and they have been taking steroid treatment for two weeks or more, they will need to wait at least 3 months after finishing the course of steroids before they can have live-virus vaccines.

Your IBD team will also recommend that your child has a regular flu injection. The nasal spray flu vaccine which is available for younger children is not recommended for those taking immunosuppressants or with weakened immune systems. This is because it contains the live forms of modified flu virus, but it should still be possible to have the inactivated injectable flu vaccine. It is best to check with your IBD team whether it would be more suitable for your child to have the nasal spray, or the injectable vaccine.

If you're planning to travel outside the UK, your child may need to be vaccinated against some of the diseases found in other parts of the world. As some travel vaccinations are live, for example,

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Our GP and Practice Nurse have been really 'on the ball' with what vaccinations my son can have, or not, and why. That has been really helpful.

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Rachel, mother to **Thomas**,
age 12, diagnosed with Crohn's
Disease in 2013

the yellow fever vaccine, as mentioned before, they may not be advisable for children with IBD on immunosuppressants. Check with your doctor which immunisations would be sensible, ideally before deciding on a destination. Certain types of meningitis vaccines can be given for visitors travelling to the Hajj and Umrah pilgrimages.

Speak to your GP or practice nurse, at least one month before foreign travel, to find out whether your child's existing UK jabs are up-to-date. They should be able to find this information on your child's medical records. Your GP or practice nurse may also be able to give you general advice about travel vaccinations and travel health, such as protecting yourself and your child from malaria. They may also be able to give you the travel jabs you need for holiday travel.

WHEN IS SURGERY NECESSARY?

Surgery for children with IBD is sometimes necessary. Once done it usually greatly improves the child's general well-being. Planned surgery should only happen after careful discussion with you and your child. In Crohn's Disease, the intestine may become very thick and cause narrowing of the space inside the tube of the intestine (a stricture). This can cause pain, particularly when eating as it can be difficult for food to pass through. Surgery may be needed to remove the affected area, widen it, or, less commonly, dilate (stretch) it. Usually key-hole assisted surgery can be considered.

As mentioned before, some children with Crohn's are prone to fistulas. A fistula is an abnormal channel connecting the bowel to the skin around the anus, or to another organ or part of the bowel. If a fistula

does not close with drug treatment, then surgery may be required. For a fistula around the anus, placing a 'seton' is the most common procedure. A seton is like a thin, loose, rubber band which sits in the fistula channel allowing it to heal better. Fistulas can often be associated with abscesses around the back passage. An abscess is a pus filled area that becomes red, swollen and painful, and in children with Crohn's, may form in the anal and rectal area. For more information about fistulas, see our leaflet: **Living with a Fistula**.

In some children with severe IBD it may be necessary to create an ileostomy. In this operation, the small intestine or ileum is brought to the surface of the abdomen and an opening is made so that digestive waste products (liquid or faeces) drain into a bag rather than through the anus. If the large intestine or colon is brought to the surface and connected in a similar way, it is called a colostomy. Both types of opening are also called stomas. A stoma may be temporary or permanent, depending on whether the colon has been removed or not. Many children with IBD and a stoma are able to continue their lives as normal, and can play sports, including going swimming.

For some children with UC, the stoma may be temporary and, in a second follow-on operation, the surgeon can make an internal pouch from the end of the small intestine. The internal pouch is also known as an ileo-anal pouch. In the procedure to form an ileo-anal pouch, after the colon has been removed, a reservoir is made from the small bowel which is then connected to the child's anus. This internal pouch means that an external bag covering the stoma is no longer needed. This procedure can have good outcomes in children. However, there are implications for the child that can come with an ileo-anal pouch, for example, possible effects on fertility. Speak to your IBD team if you have any concerns about surgery for your child.

Almost all of these operations can be performed laparoscopically (key-hole surgery), which helps to reduce the amount of pain after surgery and allows quicker recovery. Whichever operation is being suggested, your paediatric gastroenterologist will refer you to a surgeon to explain what is going to happen. Most centres also have a stoma team who specialise in helping patients with ileostomies, and should be able to meet with you and your child to talk through your concerns.

For more information see our information sheets: **Surgery for Ulcerative Colitis** and **Surgery for Crohn's Disease**.

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IS THERE A RISK OF BOWEL CANCER?

Some people with IBD do have an increased risk of developing bowel cancer, but for many there is little or no greater risk than in the general population. If someone has Ulcerative Colitis, the risk is increased when the disease is severe, affects most of the large bowel, and they have had UC for more than 8-10 years. This means that bowel cancer is uncommon in childhood. There is also an increased risk for someone with Crohn's Disease affecting all or most of the colon, a condition which is sometimes called Crohn's Colitis. If your child has Crohn's only in the small intestine, there may be an increased risk of small intestine (small bowel) cancer. However, even in the IBD population, small bowel cancer is rare.

Regular colonoscopies are usually offered to look for early warning signs of cancer in people who are at greater risk. However, most children will not need screening until they are an adult. We have an information sheet, **Bowel Cancer and IBD**, which gives more details.



3

HOW CAN I TELL IF MY CHILD IS DEVELOPING A RELAPSE?

The symptoms of a relapse or flare-up may be slightly different from those your child showed when first diagnosed with IBD. If your child has a persistent tummy ache, fever, vomiting, diarrhoea, blood in the stools, weight loss or general ill health, or if you are concerned in any way, you should consult your doctor or IBD team.

The most important thing you can do to help prevent a relapse is to encourage your child to take their medication regularly. There is also some evidence that continuing a partial liquid diet, in addition to eating a balanced diet, may have a beneficial effect in children with Crohn's Disease, and help to reduce the risk of a relapse. Some children's symptoms may be made worse by stress, and they may need extra support, for example, around exam time.

TALKING WITH HEALTH PROFESSIONALS

You may have found that you do not always have as long as you would like to talk to your GP or to the hospital specialists treating your child. To get the most out of the limited time you have during a consultation, it can be a good idea to:

- prepare by writing down any questions you have in advance, so you don't forget them,
- take a friend or relative along with you for support and help with remembering the doctor's answers to your questions,

- keep a list of your child’s medicines and a diary of your child’s symptoms and responses to treatment, so the facts are at your fingertips when you come to discuss them. If your child is a teenager, they can keep their own symptom diary. There are now online diaries or mobile phone apps which may help them keep track of their symptoms.

It is worth trying to build up a good relationship with all the health professionals looking after your child, as you may well be seeing them regularly for some years. Your child will also need to develop their own relationships and knowledge about their IBD. Don’t be afraid of asking questions when you need to know something, and encourage your child to ask their own questions too.

Many hospitals have specialist IBD nurses attached to the gastroenterology team and they are often a great source of extra information, help and support.

If you have serious concerns about a diagnosis or treatment, you can ask your GP to refer you to another specialist. This takes time however, so it may be better to try and resolve the problem with your current IBD team first. Crohn’s and Colitis UK have produced a guide on working with health professionals to get the best out of your, or your child’s IBD care, called **My Crohn’s and Colitis Care**. This guide can be downloaded from the Crohn’s and Colitis UK website: www.crohnsandcolitis.org.uk. Or you can request a printed copy by calling or emailing our helpline (see **How we can help you** for more details).

“

Since Evie was diagnosed with Crohn’s Disease, we have developed very supportive relationships with the consultants and nurses in her IBD team. It has made a big difference for us in coming to terms with her condition, and trying to keep life as normal as possible for her. ”

Ruth, mother to Evie, age 11, diagnosed with Crohn’s Disease in 2013



“

My son and I are members of Crohn's and Colitis UK, and we have used the information provided to find out more about his condition. We have found it very useful because everything is explained really well. ”



Bev, mother to **Ben**, age 18, diagnosed with Ulcerative Colitis in 2007

“

We have had information about Crohn's Disease from Crohn's and Colitis UK and our IBD Nurse. Both have been invaluable. ”



Jane, mother to **Pierce**, age 16, diagnosed with Crohn's Disease in 2016

WHERE CAN WE GO FOR INFORMATION?

Although some parents do not want to be overloaded with information, others want to learn all they can about IBD and how it affects their child. Finding out as much as you can about IBD can help you to build up confidence in yourself and your ability to respond to your child's needs. It can also make you feel more able to discuss treatment and other issues with the doctor, and to answer the questions your child asks you.

If you use the internet, it is worth trying to limit your viewing to websites that contain reliable information, such as the Crohn's and Colitis UK website: www.crohnsandcolitis.org.uk. We produce a wide range of publications about living with IBD. NHS Choices is another useful website to visit: www.nhs.uk. There are many other websites that might claim to have the true facts on IBD, but unless you can see that the information has come from a reputable and trustworthy source, it is worth being wary about what you read, as it may not be accurate. You may wish to look specifically for organisations which display the Information Standard kitemark, as this means that the information provided has gone through a rigorous process to ensure that it is clear, accurate, balanced, evidence-based and up-to-date. Speak to your IBD team if you have any doubts or concerns about where to find information about IBD.



HOW DO I COME TO TERMS WITH MY CHILD'S IBD?

It may well take time for you to come to terms with the fact that your child has a life-long condition, and that he or she may need to take daily medication for a long time or perhaps permanently. It is common to go through a period of adjustment as you get used to the idea.

“

Attending Family Network events as a family helped our daughter to understand that she is not alone in having IBD. ”

Helen, mother to Emma, age 19, diagnosed with IBD Unclassified in 2005

You can get support from parents or other people affected by IBD by contacting our helpline (see **How we can help you** for further details).

We hold a number of family events and activity days throughout the year. These are arranged in partnership with hospitals and also with the help of the Family Network volunteer team. We also work in partnership with the children’s charity Over the Wall to promote and provide residential events for children with IBD and their parents and siblings, for more information on all these activities visit: www.crohnsandcolitis.org.uk

We have around 50 Crohn’s and Colitis UK Local Networks of volunteers. You may find it helpful to attend one of their events and meet others affected by IBD. You can find out where your nearest Local Network is by looking on our website or calling our office. CICRA, the Crohn’s in Childhood Research Association, also offers help to the families of children with Crohn’s and UC. Full contact details for these services are given at the end of this booklet.

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HOW CAN I HELP MY CHILD COPE?

“

George has coped really well with his Crohn’s diagnosis. It has been hard, but we have adapted as a family, and given him our full support – including, as he’s getting older, encouraging him to take his medication himself. ”

Warren, father to George, age 15, diagnosed with Crohn’s Disease in 2014

Many parents have found that being well informed about IBD makes coping easier. Tell your child as much as you think they can understand about the condition, and try and answer any questions as honestly as possible. Some children may find some of their symptoms, such as blood in stools, scary. Try and reassure them as much as you can. Start showing your child simple ways to manage their condition, and as they get older, encourage them to take increasing responsibility for managing their own treatments and medication.

Your child, like you, will probably need time to get used to the idea that they have a long term illness. Some children seem to accept it well initially, but then, after a setback, start to feel depressed as they realise the condition is not going to go away. They may also, quite understandably, get upset about having to go through uncomfortable tests, take unpleasant tasting medicines or be seen with ‘embarrassing’ treatment aids such as a nasogastric tube. You can help by acknowledging their distress, while at the same time reminding and reassuring them that flare-ups are generally temporary, and that they are likely to feel better after the treatment.

Children often feel less isolated if they can talk to other children in a similar situation, so it can be worth trying to make contact with other families with IBD. Crohn’s and Colitis UK has the Family Network and Local Networks across the UK. We also have a Facebook forum in which young people affected by IBD can share experiences and support: www.facebook.com/groups/CCUKforum. You may find your IBD team can put you in touch with other local families.

If you think it would help your child, or you, to talk through any anxieties or concerns with someone who has experience of counselling people with ongoing illnesses, check and see whether your IBD team includes a counsellor or child psychotherapist, or can refer you to one. Your GP practice may also have a counsellor on the staff.

Try to focus on the positive - what your child can do rather than what he or she cannot do. If possible try not to restrict family life because of your child’s IBD, although you may find that if your child has a relapse, certain activities or outings have to be postponed until they feel better. Encourage your child to make the most of periods of good health, and not to use IBD as an excuse for not doing things.



PRACTICAL TIPS

There are also some practical things you could do to help your child to cope on a daily basis. Many children worry about having an ‘accident’ outside the house. It may help them to carry a small ‘emergency kit’ containing wipes, disposal bags, and spare underwear. If you are a member of Crohn’s and Colitis UK on behalf of your child, they will be sent a membership card which is also a ‘Can’t Wait’ card. This can help when asking to use toilet facilities when out and about. You can also get a Radar key from Disability Rights UK (www.disabilityrightsuk.org) that will allow your child to use disabled toilets.

HOW CAN I ENCOURAGE MY CHILD TO EAT?

“

If Alex is having a flare-up, we have learnt not to panic if he is only eating what he fancies, rather than what is healthy. But when he is well, we try to stick to a balanced diet, when possible. ”

Christine, mother to **Alex**, age 16, diagnosed with Ulcerative Colitis in 2007

Children with IBD are often thin or underweight. During flare-ups they may not be very interested in food, or they may find that eating makes their symptoms worse. Even with treatment it can be difficult for a child with IBD to eat enough to reach their ideal weight, especially during the growth spurt that occurs at puberty.

This lack of interest in food can be both worrying and frustrating for parents. You might like to try the following approach:

- Keep calm and avoid insisting that your child eats, or ‘finishes everything on the plate’. Remember, it is the condition that is making them unable to eat, not your cooking.
- Relax your rules about unhealthy food and allow your child to eat snacks and calorie-rich ‘fast’ foods, at least some of the time. If you are worried about lost nutrients, check with your child’s IBD team for advice.

- Try offering smaller meals more often during the day, or encouraging an older child to make their own small meals and snacks to eat when they feel like it.

Although children with IBD may grow more slowly than other children, four out of five should reach their full adult height. However, if you are concerned, for example, because puberty is delayed, talk to your child’s doctor. Growth charts and bone age (this can be shown by a wrist X-ray) can indicate how much growth time is left. Your specialist may refer you to an endocrinologist (growth specialist) if they feel your child may benefit from growth hormone.

“

We found some parents were well-intentioned, but were perhaps unhelpfully suggesting alternative remedies to our daughter’s prescribed medications, which we know work for her. We quickly realised that we needed to prepare for these sorts of suggestions, to show gratitude for the concern, but also to be careful not to offend if disregarding the advice! ”



Helen, mother to **Emma**, age 19, diagnosed with IBD Unclassified in 2005

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WHAT CAN I SAY TO OTHER PEOPLE ABOUT MY CHILD’S IBD?

It is up to you and your child whether and how much you tell friends, neighbours and relatives outside the immediate family. You may fear that some people will react badly to the news that your child has a chronic bowel disease. Negative reactions are most likely when people are afraid of, or don’t understand the condition. If you can be open and honest, this is usually the best way to combat any confusion or misunderstandings. It can be particularly worthwhile talking to the parents of your child’s friends, after checking with your child that they are happy about this. Other parents may, for example, be worried that your child’s condition is infectious, or that your child needs a special diet, but be reluctant to mention it until you do. You will probably find that most people are supportive once they know how they can help.

.....

WHAT IS THE BEST WAY TO APPROACH SCHOOLS AND TEACHERS?

“

Holly has been open about her condition with friends. They've been very supportive and understanding, in and out of school, which has really helped Holly to get on with everyday life. ”

Irene, mother to **Holly**, age 14, diagnosed with Ulcerative Colitis in 2015

“

The head of year has been helpful. He gave Charlie a 'time-out' card which means he can use the toilet anytime he needs to. He also has access to staff facilities that are more private. ”

Donna, mother to **Charlie**, age 16, diagnosed with Crohn's Disease in 2014

Most children with IBD attend ordinary schools, colleges and universities. School is a central part of your child's life and they should be able to take part in most activities just like any other child.

Although some children may have to miss school during relapses, the chances are that most of the time they will be well enough to attend as normal. For a few children there may be a temptation for them to use their illness as an excuse to stay off school unnecessarily. The best policy is probably to expect your child to attend school unless he or she is definitely unwell. If you are worried that your child is falling behind because of time off school, talk to the class teacher about the possibility of home tuition or extra help in class. There may be an option for the teacher to keep in touch online and send work by email to your child.

Children vary in terms of how much they want other children at school to know about their IBD. Some may appreciate a teacher explaining their condition to the class, others would find this highly distressing. It is usually a good idea to discuss this with your child before you talk to their teachers.

In general, schools are better informed now about IBD than in the past, and most teachers and other school staff are accepting and helpful once they know what is involved in your child's condition.

“

I gave the teacher the Crohn's and Colitis UK Guide for Schools, and they also shared this with the other staff that Fergus comes into contact with, so they're aware too. It was useful, for example, for reception to know as I would come in and out of school to give Fergus his liquid feed, and they would be able to point me in the direction of a room which was free for us to use.

”

Fiona, mother to **Fergus**, age 11, diagnosed with Crohn's Disease in 2010

We have an information sheet, **Children and Young People with IBD: a guide for schools**, which you may find useful when talking to your child's school. This explains IBD symptoms and likely treatments, and includes suggestions of ways in which the school can help your child, for instance by allowing them to leave the classroom to go to the toilet without asking, or to sit near the door in case of a toilet emergency. It also covers schools' legal responsibilities towards children with disabilities and medical needs, which may apply to a child with severe IBD. You may wish to give your child's teachers a copy of the information sheet.

HOW CAN I HELP MY CHILD COPE WITH STRESS AT SCHOOL?

Some parents may worry about their child being teased or picked on at school, perhaps about toilet 'accidents' or delayed physical development. Some children find it difficult to talk about this, even to parents. Signs that your child may be being bullied can include nervousness, temper tantrums, violence or sudden misbehaviour like playing truant. Talk to your child's teacher if you are worried and make sure your child knows what to do.

Some children may find that stress can make their IBD worse. This could mean that the stress of exams could trigger a relapse of symptoms. You may need to offer extra support at this time, and ensure that they do not overdo their exam preparation. Children need to find a balance between doing sufficient study to perform well, and staying well. Make sure your child has time to rest and have fun, as well as studying. It can be a good idea to check that the school is aware that exams can be a particular problem for children with a

fluctuating and unpredictable illness like IBD. Schools and colleges may be able to postpone internal exams or dates for handing in assignments, and special arrangements can sometimes be made for GCSEs and A-Levels, if necessary. A child with IBD may be covered by the Equality Act 2010, under which the school has a responsibility to make reasonable adjustments to prevent the child being placed at a disadvantage. More information about how to manage school if your child has IBD can be found in our information sheet: **Children and Young People with IBD: a guide for schools.**

HOW CAN I HELP MY CHILD MANAGE TIREDNESS AND FATIGUE?

“Weekends are planned so that Evie doesn’t get too tired. We make sure that she has some time to rest in between doing things.”

—
Ruth, mother to Evie, age 11, diagnosed with Crohn’s Disease in 2013

Fatigue can be described as an overwhelming sense of persistent tiredness, lack of energy and feeling of exhaustion that is not relieved after rest or sleep. Fatigue can be difficult to manage, particularly for children attending school, alongside extra-curricular and social activities. But some people with IBD have found ways to help reduce their fatigue. For more details about managing fatigue, see our information sheet: **Fatigue and IBD.**

CAN WE GO ON HOLIDAY WITH A CHILD WITH IBD?

“

We have travelled with our son, but we make sure we prepare well in advance. We always take a letter from his consultant with us, outlining his condition and medication, just in case. ”

—

Rachel, mother to **Thomas**, age 12, diagnosed with Crohn's Disease in 2013

“

We always take out comprehensive travel insurance, as there have been some times in the past if Alex has been very ill that we have had to postpone or cancel our holidays. ”

—

Christine, mother to **Alex**, age 16, diagnosed with Ulcerative Colitis in 2007

There is no reason why you shouldn't be able to take family holidays, although sometimes with a child with IBD these can take extra planning. For holidays abroad in particular you will probably feel more secure if you plan ahead and, once there, take the usual sensible precautions. You might find the following suggestions helpful.

- Choose destinations where you know there will be clean water and familiar food, in order to cut the risk of tummy bugs. Avoid shellfish and salads you have not prepared yourself, dairy products unless you know they have been pasteurised, and ice cream from unreliable sources, such as kiosks. Drink bottled water instead of tap water. Carrying a kit of water, wipes and anti-bacterial gel can be useful.
- Ensure you have adequate supplies of any medicines your child will need. Keep drugs in the original packaging, and if you are flying, put them in your hand luggage. (You may need to check with the airline about rules relating to liquids.) It is usually a good idea to carry a copy of a letter from your GP or hospital explaining your child's condition, and why the medication is necessary. This can also be useful to show a doctor abroad, should you need to see one. You may also want to take the contact details of your child's IBD team with you.
- Some travel immunisations may not be advisable for children with IBD, so check with your doctor which immunisations would be sensible. See **Should my child have vaccinations?**

For more tips and suggestions on managing holidays, see our information sheet, **Travel and IBD**. For more information on travelling with IBD, you might also wish to visit the IBD Passport website: www.ibdpassport.com

You may also need to think about taking out holiday health insurance before you travel. You will need to tell the insurance company about your child's IBD, and it may be more expensive because your child has a pre-existing medical condition. However, as a flare-up can happen at any time, it may be worth taking out cancellation insurance even for holidays in the UK. If you are holidaying abroad, additional insurance cover for medical expenses can be useful. Although UK travellers in Europe are covered for some of their treatment by the European Health Insurance Card (EHIC) this will not cover all the costs you may incur. Full details are on the NHS website: www.nhs.uk/NHSEngland/Healthcareabroad.

Our information sheet, **Insurance and IBD**, includes a list of insurance companies recommended by people with IBD.

IS THERE ANY FINANCIAL HELP FOR PARENTS OF CHILDREN WITH IBD?

Having a child with IBD can sometimes mean that you are incurring extra expenses such as higher heating bills, laundry costs, taxi fares and lost days at work. Some people may be able to claim Disability Living Allowance (DLA) for Children under 16 to help meet the extra costs associated with living with a long term condition.

“

Disabled Students' Allowance has meant that our daughter has been able to live in en suite accommodation at university, rather than halls of residence with shared bathroom facilities. It has made a big difference.”

Andrew, father to **Emma**, age 19, diagnosed with IBD Unclassified in 2005

We produce a guide to Claiming Disability Allowance for Children under 16 with UC and Crohn's. It is available to download from the Crohn's and Colitis UK website: www.crohnsandcolitis.org.uk

Families who are in receipt of certain benefits and who have a water meter may be entitled to a cap on their water bill. You could contact your water authority for more details.

You may also be eligible to apply for a Personal Grant of up to £500 from Crohn's and Colitis UK to help pay for an item or need which arises as a consequence of your child having IBD. There are also Educational and Vocational grants of up to £1000 for those aged 15 or over to cover education or training costs. See the Crohn's and Colitis UK website for more details: www.crohnsandcolitis.org.uk

Young people going to university or college may be able to apply for Disabled Students' Allowance (DSA). This can help meet the extra expenses that come with their condition, for example, the cost of en suite accommodation. For more information, see our leaflet: **Students with IBD: a guide for students.**

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WHAT ELSE CAN I DO TO HELP MY CHILD?

One of the most challenging aspects of being a parent of a child with IBD can be learning to let go as your child grows older and needs to become independent. Even parents of children without health problems can find this stage difficult, and if your child has a condition like IBD, it can be even harder. Nevertheless, it is important for your child to be fully in control of their condition and its treatment by the time they come to leave home.

“

I think it is vital that Ellie is involved in the everyday management of her Crohn's, which will continue with her through to her adult life. Encouraging her to ask questions of the consultants and nurses helps to make her feel she has more control over her condition. ”

Donna, mother to **Ellie**, age 11, diagnosed with Crohn's Disease in 2012

“

Holly has a couple of years left before transitioning to adult care. The process of transition was explained to us thoroughly by IBD specialists from the hospital, at a family day event, so we feel we know what to expect. ”

Irene, mother to **Holly**, age 14, diagnosed with Ulcerative Colitis in 2015

You can help prepare them for this by, for example, allowing your child to begin to take control of their own medication once you feel they are ready for this, and to meet the consultant or nurse alone, not necessarily for every appointment, but at least now and again. Encourage them to think of and ask their own questions. A good idea is to sit down together a day or so in advance, to help them make a list of things they want to say.

You should find that the hospital treating your child will also be encouraging him or her to take more responsibility once they are about 13 or 14. This will happen as part of the 'transition' process: the preparation for transfer of your child's care from paediatric (children's) to adult services. The formal transfer usually happens once a child reaches 16, although in some cases it may be delayed until your child is a little older. Different hospitals manage the transition in different ways: some have transition clinics for 16-19 year olds, others offer one or two joint appointments and some have a system of direct transfers. Ask your child's IBD team for details of your own hospital's arrangements.

Be aware that transition can be a challenging time for you and for your child, especially as it comes at a time when they will be facing other major changes in their lives. You may well be faced with the normal teenage rebellions that can occur in children of this age. Your child may suddenly want more privacy, to stay out late at night, or may become sullen, resentful and miserable. Parents may find in this sort of situation that it is better not to make concessions because your child has IBD, but to treat your child as any other teenager who has to follow the family's rules and regulations just as their siblings do.

You may find it helpful to read our booklet: **Transition: moving to adult care**. Visit our website for more information: www.crohnsandcolitis.org.uk

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HOW WE CAN HELP YOU

We produce over **45 information sheets, booklets and guides** about all aspects of IBD which are available to download for free on our website: www.crohnsandcolitis.org.uk

Our helpline is a confidential service providing information and support to anyone affected by Crohn's Disease, Ulcerative Colitis and other forms of Inflammatory Bowel Disease (IBD).

Our team can:

- help you understand more about IBD, diagnosis and treatment options
- provide information to help you to live well with your condition
- help you understand and access disability benefits
- be there to listen if you need someone to talk to
- put you in touch with a trained support volunteer who has a personal experience of IBD

Contact us by telephone on **0300 222 5700** or email info@crohnsandcolitis.org.uk

See our website for LiveChat
www.crohnsandcolitis.org.uk

OTHER USEFUL ORGANISATIONS

Crohn's in Childhood Research Association (CICRA)
www.cicra.org

CORE: the charity for research and information on gut and liver disease
www.corecharity.org.uk

IA (Ileostomy and Internal Pouch Support Group), including Young IA for children and young people
www.iasupport.org

PINNT (including Half Pinnt) - Patients on Intravenous and Nasogastric Nutrition Therapy
www.pinnt.com

British Association for Counselling and Psychotherapy (BACP)
www.bacp.co.uk

This booklet was made possible due to the support of the **Catherine McEwan Foundation***

* who had no input into the design or content of the guide.

BECOME A MEMBER TO

RECEIVE SUPPORT & INFORMATION

Free of charge publications & guides accredited by health professionals, access to support & information helplines & our member magazine full of research news & features. Membership will help you to better manage your care, for example with our Can't Wait card & through Local Networks, online advice & member only offers.

BELONG TO A COMMUNITY

Share experiences & connect with each other online, at events & through Local Networks which are supported by health professionals & policy makers. Help us raise awareness and campaign for better health services & support life-changing research to increase the knowledge of causes & best treatments.

JOINING IS EASY

You can become a member if you are 16 years or over, are a parent or carer, a health professional or if you just want to support the charity.

If you have internet access, join faster online at www.crohnsandcolitis.org.uk

ABOUT YOU

Please return this form along with payment to Crohn's & Colitis UK, 45 Grosvenor Road, St Albans, Herts, AL1 3AW
Contact the membership team on 01727 734465 if you have any queries.

Are you?

- A patient
 Crohn's Disease Ulcerative Colitis Other

Date of diagnosis

- A parent of a child under 16 years A relative of a patient
 Health professional General supporter

Name and date of birth of who you want to appear on the Can't Wait Card if not yourself (child/relative/friend)

.....

PERSONAL DETAILS

Please complete all fields and use **BLOCK CAPITALS**:

Surname Title

First name Gender Male/Female

Address

.....

..... Postcode

Email

Telephone number

Mobile number

Date of birth ____/____/____ Ethnic group

Occupation

PAYMENT DETAILS

Individual membership

- £15 per year Direct Debit
 £19 per year Cheque/Credit or Debit Card

If you are a student, are experiencing financial issues or on a low income due to health or employment issues then please contact the membership team on 01727 734465 to discuss joining at a reduced rate.

1. Please make cheques payable to Crohn's and Colitis UK.
2. If you would like to pay by credit card please call the membership team on 01727 734465 or join online at www.crohnsandcolitis.org.uk.
3. Direct debit is the most efficient way to pay. If you would like to pay by direct debit please Fill out the form below

Subscription £ Additional donation £ **TOTAL £**

By Direct Debit



Instructions to your Bank or Building to pay by Direct Debit

Amount to be taken £ Every month Every year

Name(s) of account holder(s)

Name of Bank/Building Society

Branch name

Bank Building society account number

Sort code

Date

 / /

Organisation ID

OFFICIAL USE ONLY

OUR REFERENCE

Instructions to your Bank or Building

Please pay Crohns and Colitis UK Direct Debits from the account detailed in this Instruction subject to the safeguards assured by The Direct Debit Guarantee. I understand that this Instruction may remain with the Crohns and Colitis UK and, if so, details will be passed electronically to my Bank/Building Society.

Signed _____ Date _____

Gift aid your donation at no extra cost: I wish to gift aid my donation and any donations I make in the future or have made in the past 4 years to Crohn's and Colitis UK. I am a UK tax payer and I understand that if I pay less Income Tax and/or Capital Gains Tax in the current tax year than the amount of Gift Aid claimed on all my donations it is my responsibility to pay any difference.

Yes I am a UK tax payer and would like to gift aid *please tick* No, I am not a UK tax payer *please tick*

Data protection

Crohn's and Colitis UK will hold the information you have given on this form and will use it in connection with your membership and to keep you informed about the activities of the Charity. A copy of our Data Protection policy is available on request. At all times we comply with the Data Protection Act 1988.

From time to time we may want to contact you regarding the general work of the charity, tick here if you would not like to receive this information.

We could not do what we do without the support of our members so are always very grateful for any additional donations that you may be able to give

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