

Improving life for
people affected
by inflammatory
bowel diseases



IBD in Children: a parent's guide



Crohn's and Colitis UK is the working name of the National Association for Colitis and Crohn's Disease (NACC). NACC is a voluntary Association, established in 1979, which has over 30,000 members and 70 Groups throughout the United Kingdom.

Membership of the Association costs £12 a year. New members who are on lower incomes due to their health or employment circumstances may join at a lower rate. Additional donations to help the work of the Association are always welcomed.

Crohn's and Colitis UK's publications are research based and produced in consultation with patients, medical advisers and other health or associated professionals. They are prepared as general information on a subject with suggestions on how to manage particular situations, but they 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.

We hope that you find the information helpful and relevant. We welcome any comments from readers, or suggestions for improvements. References or details of the research on which this publication is based, and details of any conflict of interest, can be obtained from Crohn's and Colitis UK at the address below. Please send your comments to Helen Terry at Crohn's and Colitis UK, 4 Beaumont House, St Albans, Herts AL1 5HH or email h.terry@crohnsandcolitis.org.uk.

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Introduction

In the UK, one person in 250 has Crohn's Disease or Ulcerative Colitis, conditions collectively known as Inflammatory Bowel Disease or IBD. These illnesses can start in childhood: although IBD is rare in children under 2, it becomes increasingly common in teenagers and young adults.

If you have a child with Inflammatory Bowel Disease, it's natural at times to feel isolated and worried about how you will cope, especially when your child is first diagnosed. The important things to bear in mind are 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 the medical treatment is to reduce and 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.

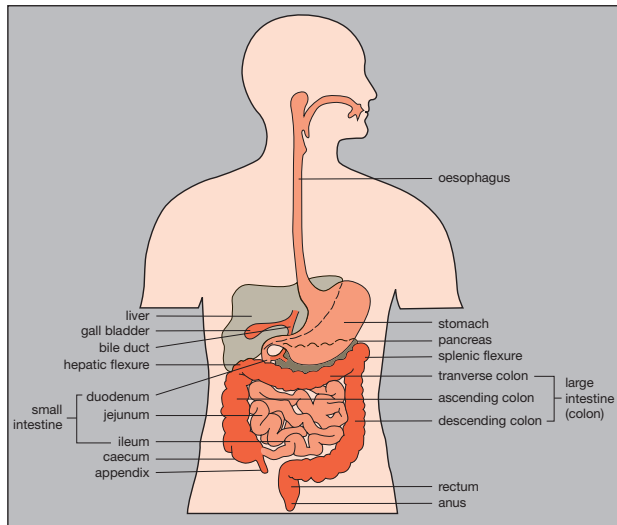
This booklet has been produced to help you understand your child's condition and the treatments that may be used. It also looks at some of the more general concerns that you may have as a parent, and includes suggestions based on the experiences of other parents of children with Ulcerative Colitis or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

If you would like to speak to someone who understands what it is like to be a parent of a child with IBD, contact Crohn's and Colitis UK's Parent to Parent service by phoning our Information Line on 0845 130 2233. Staffed by trained volunteers all of whom have had a child with IBD, Parent to Parent offers confidential telephone support for parents of children and young people up to and including the age of 21. There is also a more general supportive listening service, Crohn's and Colitis Support, on 0845 130 3344, which you may find helpful.

Copies of all our information sheets and booklets can be obtained by calling the Information Line, emailing info@crohnsandcolitis.org.uk, or downloading them from our website: www.crohnsandcolitis.org.uk. Another service on this site is *IBD and Me*, a website discussion forum for young people aged 16-29.

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 best known. It is not always possible to distinguish between the two, and then the terms indeterminate colitis or IBD unclassified (IBDU) may be used, and this is commonly a diagnosis given to children. If Ulcerative Colitis affects only the rectum it is called proctitis.



IBD is not the same as IBS (Irritable Bowel Syndrome) nor is it infectious.

This diagram shows the main features of the digestive system. When food is swallowed it goes down the oesophagus, into the stomach, where the digestive process starts. The food then moves into the small intestine where most of the goodness is absorbed. Liquid waste then passes from the small intestine into the colon (large intestine). The colon absorbs the water and the waste becomes solid faeces (stool or 'poo') which then pass out of the body through the anus.

In IBD, the intestines, which are also called the bowels or the gut, become swollen and inflamed (red and sore).

Crohn's Disease can affect any part of the digestive system, from the mouth to the anus. However 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 (large intestine). In this disease the inner lining of the colon becomes inflamed and develops many tiny ulcers on its surface.

What are the main symptoms?

Crohn's Disease and Ulcerative Colitis are chronic, or ongoing, conditions. This means that they are diseases which may give trouble over a number of years. However there may be long periods of good health (remission) alternating with times when the symptoms are more active (relapses or 'flare-ups').

The early symptoms of Crohn's Disease are often very vague and can vary from person to person, so the diagnosis may not be clear at first. With children, the main symptoms are usually stomach or tummy ache, and diarrhoea, which may be blood stained. Crohn's can also cause nausea, vomiting and constipation. Most children with Crohn's tend to feel tired and lack energy. Loss of appetite is another very common symptom which can lead to dramatic weight loss and, in the longer term, poor growth.

Ulcerative Colitis can also cause abdominal pain, and as with Crohn's, your child may feel tired and lethargic. The main symptom, however, tends to be persistent diarrhoea, which can often be quite severe, and usually contains blood and mucus. Occasionally UC may cause constipation.

What causes IBD?

In spite of much research the exact cause of IBD remains uncertain. We do know that IBD is not infectious and is not a form of cancer. It is almost certainly not caused by stress or worry, although some people with IBD have found that stressful situations seem to trigger a flare up of their symptoms.

Many researchers now believe that IBD is caused by a complex interaction of factors: the genes a person has inherited which may predispose them to develop IBD, and then an abnormal reaction of the immune system (the body's protection system) to certain bacteria in the intestines, possibly triggered by something in the environment. Viruses, bacteria, 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. Both UC and Crohn's are known to occur more often in some families than in others, and in recent years progress has been made in identifying the genes that may be involved in making people more likely to develop IBD. It is now thought that if one parent has IBD, the lifetime risk of a child developing IBD is about 2% for UC and 5% for Crohn's, although it may be higher in some population groups. That is, for every 100 people with IBD, about 2 (UC), or about 5 (Crohn's), of their children might be expected to develop IBD at some time in their lives. However, we still cannot predict exactly how IBD is passed on from one generation to another.

There has in the past been considerable press coverage linking IBD to the MMR vaccine. This possibility has now been extensively researched and the balance of expert opinion is that such vaccines do not cause IBD. If you would like more information about this, contact the Crohn's and Colitis UK Information Line. Another possibility is an association with Mycobacterium Bovis, a bacterium which can contaminate milk. This theory is still being debated by the medical profession. Again, contact the Information Line for more details

Can other parts of the body be affected?

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.

Skin rashes are quite common, and sometimes come on at the start of an attack. One type of rash, erythema nodosum can cause small painful red patches down the shins. This too should disappear with the treatment of the IBD.

Eyes can also be affected, becoming sore and red. This is not usually serious and can be treated with eye drops. Occasionally more serious eye problems occur, so if the symptoms continue, it is important for your child to see an eye specialist.

The liver can be affected in people with IBD, but it is rare in children. Your doctors should screen for liver problems, such as ongoing inflammation, through routine follow up blood tests.

What tests may 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.

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 samples will also be tested, to exclude infectious diarrhoea.

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, 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 endoscopist to get a clear look at the internal lining of the intestine and to take a biopsy (a small scraping of tissue) through the endoscope. The biopsy is then examined under a microscope and this helps with the 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, they can be done under heavy sedation given into a vein in the arm. If your child is having a colonoscopy he or she will 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 this at home before coming in to the hospital, and it can be helpful to talk this through beforehand with the doctor or nursing staff, so you know just what to expect.

You will be asked to sign a consent form for an endoscopy. If you still have any worries and 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 and you may find the hospital or centre has a booklet on endoscopies written especially for children and their parents.

Upper GI endoscopies and colonoscopies cannot tell us about the section of the small intestine the endoscope cannot reach, so other tests may also be used, such as a capsule endoscopy, a barium meal test or an MRI scan of the small bowel.

In a capsule endoscopy, your child swallows a capsule about the size of a jelly baby, which sends back photographs to an external computer as it goes through the gut. As yet however, capsule endoscopies are not available in all hospitals, and would not be used for children who may have strictures (narrow sections) in their intestine, as can happen with some types of Crohn's Disease.

A barium meal and follow through test is a special x-ray which 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 similar liquid before having the test.

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

For more information about tests see our booklet *Investigations for IBD*.

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 could be very ill with IBD, there will probably be periods of remission when their symptoms more or less disappear.

What kinds of treatment are there?

Since IBD affects everyone differently, your specialist will suggest the best treatment plan for your child's condition at that time. The aim of the treatment will be to make your child feel better, and then to keep their symptoms under control. There are several kinds of treatment for each condition, and these may be used one after another, or in combination, at the same time.

Crohn's Disease may be treated with dietary treatment (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 have shown that for some children it can be as effective as steroids (see drugs used below). It usually involves taking a special liquid diet, instead of food, for a number of weeks. The majority of children respond very well to such 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.

The treatment of Ulcerative Colitis and IBDU/indeterminate colitis is more like that of adults: the main focus of treatment is usually drug therapy, although in some children surgery is needed. Unlike Crohn's, Ulcerative Colitis cannot be treated with a liquid diet, although supplementary nutritional drinks are sometimes recommended to provide extra energy (calories) for growth.

How does dietary treatment work?

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 or Elemental 028, 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 diet drinks 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 throughout the day and each one taken over 20 to 30 minutes or so. 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 brand or type of food that your child is able to drink without a tube. Your dietitian or IBD team should be able to help with this. Once in place a nasogastric tube can remain for many weeks and 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. The time that the actual feed is given can still be organised to suit your child's daily routine, and some of it can be given overnight while your child is asleep.

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 can also 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.

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 from time to time, 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 a specific food 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 about how food affects IBD, and includes suggestions for healthy eating with UC and Crohn's.

What drugs are used for IBD?

The drugs used to treat IBD act to stop the inflammation and to lessen the chance of a relapse or flare up. As the symptoms are relieved, so your child should feel much better. As with many drugs however, there may be unwanted side effects, so they are used very carefully in the smallest doses to give the desired result.

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

- **Aminosalicylates**, such as sulphasalazine 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 seems well. You may worry about your child taking medication long-term, but it may help to keep things on an even keel, especially when your child is growing.
- **Corticosteroids**, often called simply 'steroids', such as prednisolone and budesonide, are given to treat acute IBD symptoms and often act very quickly to control the discomfort. These can have side effects such as a rapid weight gain and your child's face may get chubbier. 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. Steroids are also known to affect children's growth, so the number of treatments and the total dose are usually kept to a minimum, and these side effects usually go as the drug dose is reduced. When only the lower part of the colon or the rectum is affected, steroid enemas or suppositories (medicine that can be inserted into the body through the rectum) can be used. These cause fewer side effects as less of the drug is absorbed into the body.
- **Immunosuppressants**, such as azathioprine, and 6-mercaptopurine (6MP) may be introduced immediately or following a relapse. They may also be used for children who have become steroid dependent. They are slow acting and can take 6-12 weeks before being fully effective.

These drugs reduce inflammation by suppressing the immune system, and at the beginning of treatment can cause nausea, vomiting and loss of appetite. It is particularly important that your child has regular blood checks while on this type of medication as it can also suppress the production of blood cells in the bone marrow. If this happens, the drug can be stopped or the dose can be adjusted.

Other immunosuppressants such as methotrexate or ciclosporin may be used if your child has not responded to azathioprine or 6MP.

- **Biologics**, such as infliximab and adalimumab, are newer drugs which may be helpful if your child has Crohn's Disease or acute severe UC that is not responding well to other treatments. They work with the immune system to block chemicals that cause ongoing inflammation and usually have to be given via an intravenous infusion (a drip into a vein) or by injection. Research is still continuing into the best way to use biologics for IBD. For some conditions and for some children, surgery may be suggested as an option

Your IBD team will be monitoring your child's health very closely and should be able to explain in more detail how the medication being prescribed will work. We have a general booklet on drug treatment: *Drugs used in IBD*, which you may find helpful, and there are also individual individual drug information sheets about commonly used immunosuppressants and biologics.

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 good way to ensure this is for your child to carry a 'Steroid Card' or wear an emergency bracelet.

Steroids and immunosuppressants can reduce your child's resistance to infection. Some infectious diseases, such as chicken pox, can be serious, and you should 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.

Your child must not receive certain live vaccines while on steroids or immunosuppressants. This includes the MMR (measles, mumps, and rubella) and BCG (tuberculosis) vaccines. For polio, an 'inactive' vaccine can be given instead of the live one. It is best to check with your IBD team before your child has any vaccination.

When is surgery necessary?

Surgery is sometimes necessary in childhood, more commonly for Crohn's than for Ulcerative Colitis. Once done it usually greatly improves the child's general well-being. Surgery will only happen after careful discussion with you and your child.

With Crohn's Disease the intestine may become very thick which can result in a narrowing or 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, or, where possible, dilate (stretch) it.

Some children with IBD are prone to fistulae. A fistula is an abnormal channel connecting the bowel and 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.

In some children with severe IBD it may be necessary to carry out an ileostomy. In this operation the colon is removed and a small opening or stoma is made in the surface of the abdomen.

Waste is then collected in a stoma bag. For some children with UC a permanent ileostomy can be avoided by the surgeon making an internal pouch from the end of the small intestine. This means they do not need an external bag. However, this alternative is not always an option. Whichever operation is being suggested, your 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 beforehand and talk through your concerns. This type of operation is often well tolerated in children, so that they feel much better after surgery.

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

Is there a risk of 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. 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 the Crohn's Disease affects only the small intestine, it is much less likely for cancer to occur.

Regular colonoscopies are usually offered to look for early warning signs of cancer in people who are at greater risk. We have an information sheet, *Bowel Cancer and IBD*, which gives more details.

How can I tell if my child is developing a relapse?

The symptoms of a relapse 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 may have a beneficial effect on IBD symptoms and so help 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.

Can my child lead a normal life?

Although there is no cure for IBD, the aim of treatment is for your child to lead a normal life, especially when in remission, and a lot can be done to try to keep your child symptom-free. Most children with IBD can continue to go to school and take part in sports and other interests. Many then go on to college or university, and eventually start a family of their own.

Where can I get information and support?

It may well take time for you to come to terms with the fact that your child has an ongoing disease, 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 'grieving' as you get used to the idea.

"You blame yourself, what did you do that gave your child this problem? The answer is, nothing, but you feel guilty. As a parent you feel it's your job to keep your child safe and well, and you can't, because you have no control over the disease. Talk to people – you are not alone, never bottle it up."

(Mum of an 11yr old with UC)

You may want to talk to other parents about how you feel: Our Parent to Parent service is a telephone helpline staffed by volunteers all of whom have had a child with IBD. To make an appointment for one of these volunteers to call you, contact the Information Line. There is also a

more general supportive listening service, Crohn's and Colitis Support, which you may find helpful. This is also run by volunteers with personal experience of IBD. Smilie's Network is a special group within Crohn's and Colitis UK that offers support to families with a child or young person with IBD. It arranges activities and events for both children and parents and can be contacted through the Crohn's and Colitis UK office and website. 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.

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 build up confidence in yourself and your ability to respond to your child's needs. It can also make you more confident about discussing treatment and other issues with the doctor, and answering the questions your child asks you.

"We found that if we talked in a knowledgeable way, it helped us build up a good relationship with all the health professionals we dealt with."

(Mum of a 15 year old with Crohn's Disease)

There is a variety of books specifically about IBD. Visit the health section of your local library or look on our website: www.crohnsandcolitis.org.uk. This is one of the most comprehensive websites devoted to IBD and most of our publications can be downloaded directly from this site. Both CICRA and CORE, the charity for research and information on gut and liver disease, also have helpful websites and can provide free leaflets on Crohn's Disease and UC. CICRA can be reached at www.cicra.org.uk and CORE at www.corecharity.org.uk.

There are some excellent more general websites which carry information on IBD. Useful sites include:

- NHS Direct: www.nhsdirect.nhs.uk
- NHS Choices: www.nhs.uk
- BBC Health Online: www.bbc.co.uk/health
- Net Doctor www.netdoctor.co.uk
- Embarrassing Problems: www.embarrassingproblems.com
- Surgery Door: www.surgerydoor.co.uk

There is also a discussion forum for 16-29 year olds with IBD, called *IBD and Me*, on the Crohn's and Colitis UK website

How can I get the most from my time 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.

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

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. Do not be afraid of asking questions when you need to know something, and encourage your child to ask their own questions too.

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.

How can I help my child cope?

Any long term illness is likely to have an effect on the family and there is no doubt that a calm and positive attitude is helpful. Many parents have found that being well informed about IBD makes this 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, rather frightening; 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, may begin to feel depressed as they realise the disease 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 should 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 Smilies Network, local groups across the UK, and a pen pal page for our members. You may also 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. Your GP practice may also have a counsellor on the staff. Our information sheet *Counselling for IBD* has more details on how to find a counsellor.

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.

"We try very hard not to let the disease dictate our lives. We make the most of periods when his health is good and often take off for weekends at short notice, something we never did before he was ill."

(Mum of a 7yr old with IBDU)

How can I encourage my child to eat?

Children with IBD are often thin and even underweight. During flare-ups they tend to stop eating, partly because of lack of appetite and partly because they fear it may make 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 during puberty.

This lack of interest in food can be both worrying and frustrating for parents. You may 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, they generally catch up in the end. However, if you are concerned, for example, because puberty is delayed, talk to your doctor. Growth charts and bone age (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.

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 about your child's IBD. 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?

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 will have to miss school during relapses, 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 exploit their illness 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.

"I always tried to get her to go to school despite tummy aches. I was pushing to make life as normal as possible. After all, it's a condition she has to live with. If I treated her like an invalid she would all too readily fulfil that role."

(Mum of a 9 year old with UC)

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.

“We took the information about IBD into school and asked for it to be shown to everyone, from teachers to dinner ladies. Now the school fully understands what he has to cope with, they are very helpful, and do their utmost to make his school life happy.”

(Mum of a 7 year old with UC)

How can I help my child cope with stress at school?

Occasionally, children with IBD get 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. Childline can also offer advice and support (0800 1111).

For some children the stress of exams can 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 working. 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 can often postpone internal exams or dates for handing in assignments, if necessary, and special arrangements can sometimes be made for GCSEs and ‘A’ levels.

Can we go on holiday with a child with IBD?

There is no reason why you shouldn't be able to take regular 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 do plan ahead and, once there, take the usual sensible precautions. You may find some of the following suggestions helpful.

- Choose destinations where you know they will have 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.
- Make sure the whole family is scrupulous about washing hands after going to the toilet and before touching food. Carrying a kit of water and antibacterial wipes 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.
- Discuss with your doctor whether it would be a good idea to take some antibiotics with you on holiday in case a tummy bug strikes.
- Some travel immunisations may not be advisable for children with IBD, so check with your doctor which immunisations would be sensible, ideally before deciding on a destination.

“We have been to Crete and Florida with her UC, gastrostomy, feed, pump and various meds – we are not letting it stop us living life to the full.”

(Mum of a 14 year old girl with UC)

For more tips and suggestions on managing holidays, see our information sheet, *Travel and IBD*. You may also like 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 Department of Health's Website www.dh.gov.uk/travellers, and in the leaflets available from the Department on 0845 606 2030, and at the post office. These also contain an application form for the EHIC.

Our information sheet, *Insurance and IBD*, includes a list of sympathetic insurance companies suggested by members.

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 and taxi fares. Some people may be able to claim Disability Living Allowance (DLA) to help meet these costs.

The current rules are that to be eligible for DLA your child must have a long term health problem, such as severe IBD, that affects their everyday activities, that has lasted for at least three months and is expected to last another at least another six. This health problem has to result in your child needing substantially more care or supervision than other children of the same age. If your child is under 16 you can claim on their behalf. If they are 16 or over they can claim in their own right.

It doesn't matter if you do not consider your child to be 'disabled'. For the purposes of DLA, 'disabled' simply means that your child has a long term illness which affects their everyday activities. Your child will not be 'registered disabled' if they receive DLA and it should not make it more difficult to get a job when they become an adult. DLA is not means tested and your financial circumstances are not taken into account.

Crohn's and Colitis UK publishes an information sheet, *Claiming Disability Allowance: a guide for children under 16 with UC and Crohn's Disease*, which is updated to reflect any changes in legislation. There is also a similar guide for adults over 16.

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 an illness like IBD, it can be even harder. Nevertheless, it is important for your child to be fully in control of their illness and its treatment by the time they come to leave home.

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 be happening 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 transfer 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. You may also find Crohn's and Colitis UK's *Transition* booklets helpful. These are published in association with CICRA and include a guide for young people, as well as one for parents.

Be aware that transition can be a challenging time for your child too, 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 occur in virtually all children of this age. Your child may suddenly want more privacy, to stay out late at night, or become sullen, resentful and miserable. Most parents have found that in this sort of situation it is better not to make concessions because your child has IBD, but to treat your child as a normal teenager who has to follow the family's rules and regulations just as their siblings do.

Help and Support from Crohn's and Colitis UK

- Our website is at **www.crohnsandcolitis.org.uk**
- The **Crohn's and Colitis UK Information Line: 0845 130 2233** is open Monday-Friday 10am–1pm, excluding bank holidays. There is an answerphone service outside of these hours. Email info@crohnsandcolitis.org.uk
- **Parent to Parent** can be contacted through the Information Line.
- Our supportive listening service **Crohn's and Colitis Support: 0845 130 3344** is open Monday-Friday 1pm-3.30pm and 6.30-9pm. This is staffed by trained volunteers with experience of IBD.
- Copies of all the publications mentioned in this booklet and a full list of our other information sheets and booklets can be obtained by calling the Information Line or emailing info@crohnsandcolitis.org.uk. Most can also be downloaded from our website.
- **Smilies Network** and the **IBD and Me** discussion forum can be contacted via the Crohn's and Colitis UK website.

Other useful organisations

Crohn's in Childhood Research Association (CICRA)
Parkgate House, 356 West Barnes Lane
Motspur Park, Surrey, KT3 6NB
020 8948 6209
Website: www.circa.org email: support@circa.org

CORE: the charity for research and information on gut and liver disease
Core, 3 St Andrews Place, London, NW1 4LB
020 7486 0341
Website: www.corecharity.org.uk email: info@corecharity.org.uk

IA (Ileostomy and Internal Pouch Support Group),
including Young IA for children and young people
Peverill House, 1-5 Mill Road
Ballyclare, Co Antrim, BT39 9DR
0800 018 4724 or 028 9334 4043
Website: www.the-ia.org.uk email: info@iasupport.org

PINNT (including Half Pinnt) (an organisation for patients on
intravenous and nasogastric nutrition therapy)
PO Box 3126
Christchurch, Dorset, BH23 2XS
Website: www.pinnt.com email via website

Crohn's and Colitis UK

4 Beaumont House, Sutton Road, St. Albans, Hertfordshire AL1 5HH.

Information Service: 0845 130 2233
Administration: 01727 830038
Fax: 01727 862550
Crohn's and Colitis Support: 0845 130 3344

Email: info@crohnsandcolitis.org.uk

Website: www.crohnsandcolitis.org.uk

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