

**CROHN'S &
COLITIS UK**

Supporting your child with Crohn's or Colitis



ABOUT THIS BOOKLET

It's never easy seeing your child unwell. And it's natural to feel worried about what living with Crohn's or Colitis could mean for them and your family. But there's lots you can do to help your child live life to the fullest. And we're here to help, every step of the way.

This booklet explains how Crohn's or Colitis might affect your child, what treatments they may be given and shares tips to help you and your child manage the day-to-day challenges of living with their condition. There's a lot of information here, and that might feel overwhelming – so we'd recommend just dipping in and out of the relevant sections as and when you need to. This booklet is for parents of children under 16 but may also be helpful for parents of older children.

We write our information together with people affected by Crohn's and Colitis, health professionals and other experts. The content is based on up-to-date, unbiased, evidence-based research. We don't recommend any particular products, and this information isn't meant to replace medical advice. Please speak to your GP or IBD team before making any changes.

If you'd like more information about how we've written this, the evidence we've used, or if you have any comments or suggestions for improvements, please email the Knowledge and Evidence Team at: **evidence@crohnsandcolitis.org.uk**.

You can also write to us at Crohn's & Colitis UK, 1 Bishops Square, Hatfield, Herts, AL10 9NE or contact us through our Helpline on **0300 222 5700**.

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ABOUT CROHN'S & COLITIS UK



We're the UK's leading charity for Crohn's and Colitis. We're working to improve diagnosis and treatment, and to fund research into a cure; to raise awareness and to give people hope, comfort and confidence to live freer, fuller lives. We're here for everyone affected by Crohn's and Colitis.

This publication is available for free thanks to the generosity of our supporters and members.

By supporting us, you can make a real difference to people's lives. Find out more by calling **01727 734465** or visiting **crohnsandcolitis.org.uk**

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YOUR CHILD HAS JUST BEEN DIAGNOSED

Finding out your child has Crohn's Disease, Ulcerative Colitis or Inflammatory Bowel Disease Unclassified (IBDU) can stir up a range of emotions. But you're not alone. There are thousands of other parents in a similar situation with similar experiences and concerns. More than 300,000 people in the UK are living with Crohn's or Colitis. We're here to help you and your child through this, so you can feel positive about the future.

You may not have heard of Crohn's or Colitis before. They are types of Inflammatory Bowel Disease (IBD) – we'll explain the differences between the conditions later in this booklet, but in IBD parts of the gut (digestive system) become swollen, inflamed and ulcerated. This can cause pain, diarrhoea, weight loss and tiredness – but your child may have other symptoms too. Crohn's and Colitis are chronic conditions, meaning they're lifelong.

These conditions are unpredictable and your child will likely have periods of good health, known as remission, and times when their condition is active, known as flare-ups or relapse. Treatment aims to control your child's symptoms and help them stay in remission.

Coming to terms with your child's diagnosis

Coming to terms with your child's diagnosis can take time. It's common to go through a period of adjustment as you get used to everything, learn more about their condition and find your own ways of coping.

Many parents feel guilty or even blame themselves for their child's condition. **You must remember that it's not your fault – nothing you did or didn't do will have caused your child to develop Crohn's or Colitis.**

The up and down nature of Crohn's and Colitis can make it difficult to deal with. Some times are harder than others, for example, if your child is having a bad flare-up or getting unpleasant side effects from their medicine. You may feel at a loss because you don't know how to make them feel better. There's no single right answer most of the time, and when you have to make difficult decisions, remember that it's in the best interests of your child.

There will also be times when your child is well, living life to the fullest and finding success in their studies, jobs and personal pursuits. Your child is still your child and their condition is only part of who they are.

Everyone copes differently – there is no right or wrong way of doing things. Some parents feel more in control if they learn all they can about their child's condition, whereas others prefer to take things one step at a time. We have a confidential helpline and a range of publications that explore many aspects of Crohn's and Colitis. See the section **Support for you**.

Will my child get better?

Crohn's and Colitis can't be cured or taken away completely, but a lot can be done to help your child live a normal life. Many of your child's symptoms should improve after they start treatment. There may be periods of relapse when your child is unwell, but there will also be periods of remission when their symptoms more or less disappear.

“

It's easy to think 'is it my fault in some way? Could I have done something to prevent this from happening?' The truth is that no you couldn't and no it's not your fault. ”

—
Lee, father of Sam, age 12, living with Crohn's Disease

How will Crohn's or Colitis affect my child's life?

Crohn's and Colitis affect everyone differently. The conditions are fluctuating and unpredictable, and symptoms can change from one day to the next. Some children's conditions rarely bother them, whereas others need lifelong medication or surgery.

Most children with Crohn's or Colitis continue to go to school and take part in sports and other interests. There's no reason why your child won't be able to go on to further education, training or employment, successfully have a family of their own and enjoy their life.

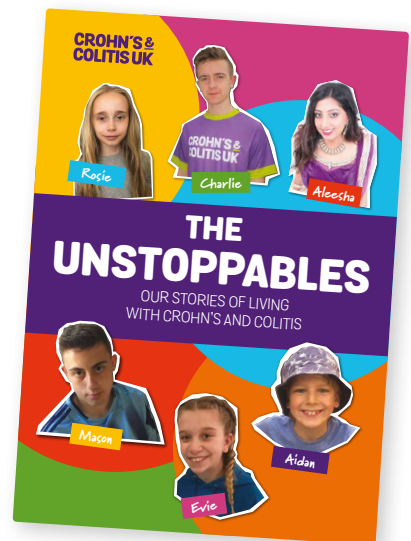
Although your child's journey through life may be different to the one you anticipated, children are very resilient, and many take it in their stride. Your child may have to slow down or take a break at times, but for many children their condition won't stop them doing the things they love.

“

Being diagnosed hasn't stopped me or changed my life much. I still train six hours a week with my gymnastics team and have competed regularly. Life becomes a bit different but it's really just about remembering to do a few more things, like taking your medication. ”

Rosie, age 10,
living with Crohn's Disease

Rosie is one of six young people who share their personal story of living with Crohn's or Colitis in our booklet **The Unstoppables: Young People**.



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SUPPORT FOR YOU

Looking after a child with Crohn's or Colitis can feel overwhelming at times and the stigma surrounding the conditions can make people feel isolated and alone. It's important that you ask for help when you need it and take care of yourself as well as your child.



Support from your child's IBD team

Your child's IBD team understand that a new diagnosis of Crohn's or Colitis can be challenging and distressing for your child – and for the whole family. They should be your first point of call for any medical concerns or questions you have. IBD teams often include paediatric gastroenterologists (children's doctors in gut diseases), IBD Nurse Specialists, and in some cases psychologists who can offer emotional support to your child and your family. Ask your child's IBD team for more information about this.

IBD Specialist Nurses are a great source of information, help and support. You can find your local IBD nurse at crohnsandcolitis.org.uk/ibd-nurse

Build a good relationship with your child's IBD team, as you'll probably see them regularly for some years. Your child will need to develop their own relationships with their team and knowledge about their condition.

If you have serious concerns about a diagnosis or treatment, you can ask your GP to refer you to another specialist. This takes time, so it may be better to try to resolve the problem first. You may find it helpful to look at the IBD Standards. The IBD Standards set out what high-quality care looks like at every point of the patient journey, from pre-diagnosis, to surgery and ongoing care, as well as how the IBD Service should be organised to deliver this. You can see the IBD Standards at ibduk.org/ibd-standards



PRACTICAL TIPS

Making the most of the time with your child's IBD team

You don't always have as long as you'd like to talk to the doctors and specialists treating your child. To get the most out of the limited time you have, you could:

- Write down any questions you have in advance, so you don't forget them.
- Be open to asking any questions you have, even if it's a small thing, chances are they've heard it before and can help.
- Take a friend or relative along with you for support and help remembering any answers.
- Keep a list of your child's medicines and a diary of their symptoms and responses to treatment, so you have all the facts to hand.
- If your child is older, they can keep their own symptom diary, or use apps like **My IBD Care**.



“

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,
living with Crohn's Disease

Information



The more you know about Crohn's or Colitis, the more confident you'll be in responding to your child's needs. You'll be better able to discuss treatments and other issues with your child's doctor and IBD team, and

answer your child's questions.

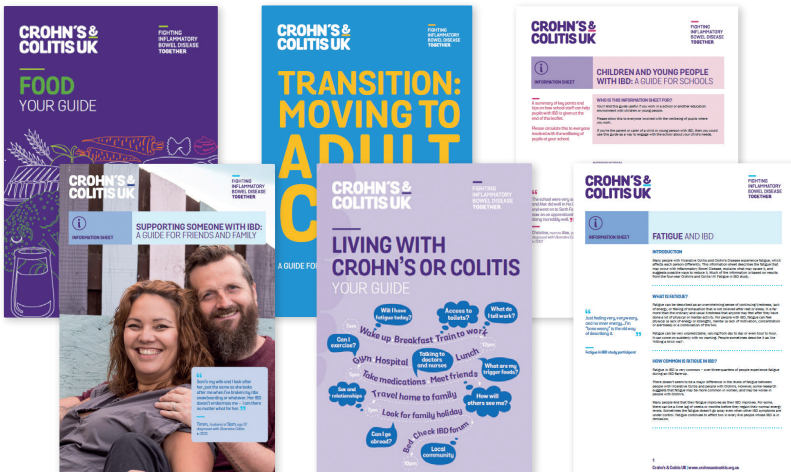
Limit your internet research to websites with reliable information such as crohnsandcolitis.org.uk and nhs.uk. If you can't see that the information has come from a trustworthy source, be wary as it may not be accurate – and keep in mind that everyone experiences the conditions differently.

We have a range of information about all aspects of living with Crohn's or Colitis. See

“

My son and I are members of Crohn's & 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, living with Ulcerative Colitis





crohnsandcolitis.org.uk/publications

Helpline

Our Helpline offers a confidential service for anyone affected by Crohn's or Colitis. Our team can provide general information and answer any questions you might have about the conditions.

You can contact the Helpline by:

Phone: **0300 222 5700**

Email: helpline@crohnsandcolitis.org.uk



Live chat: crohnsandcolitis.org.uk/livechat

Local Networks

We have around 50 Local Networks of volunteers across the UK that bring local people affected by Crohn's and Colitis together. They run a range of events, from educational talks to socials. Check our website or call our Helpline to find out where your nearest Local Network is at crohnsandcolitis.org.uk/localnetwork

Parent/Carer and Child Membership

You can join Crohn's & Colitis UK as a member if you have a child under 16 with the condition. For member benefits and details, see crohnsandcolitis.org.uk/membership

Support from family and friends

Asking others for help is hard, but it doesn't mean that you aren't coping. Your family and friends may want to help but just don't know how.

Think about how your family and friends can best support you. You could ask them to:

- Take your child to their appointment.
- Stay with your child in hospital while you go home to wash, sleep or take a break.
- Pick up your child's prescription or run some errands for you.
- Collect your other children from school.
- Look after your child so you can spend time with your other children.

Making time for you

You shouldn't feel guilty about taking time out for you. Keeping well in your own mind and body is important – even if it's sometimes hard to find the time. You'll be much better able to look after your child if you look after yourself and feel refreshed. Try taking a walk, doing some exercise or practicing mindfulness, or simply spending time with your partner or friends doing something you enjoy.

“

You know your child and their circumstances – choose what you want to listen to and don't let yourself get overly frustrated by the opinions of others. You learn to try to educate people – or to just brush it off! ”

Rob, father to **Harry**, age 11, living with Crohn's Disease

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ABOUT CROHN'S AND COLITIS

About Crohn's and Colitis

Crohn's Disease and Ulcerative Colitis are Inflammatory Bowel Diseases that cause painful ulcers and inflammation in the gut (digestive system). It's not always possible for doctors to tell the difference between Crohn's or Colitis, so your child may be diagnosed with IBD Unclassified (IBDU) or Indeterminate Colitis. These conditions are lifelong (chronic) and can be diagnosed at any age, although they're less common in very young children and babies.

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.

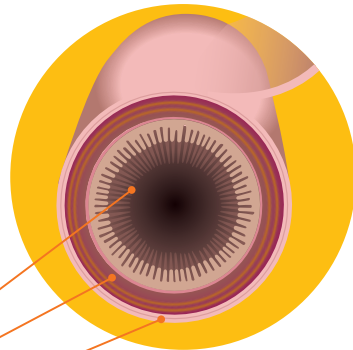
The bowel

The bowel is a long tube, coiled up inside you. The bowel is part of the gut that takes in food and carries out waste (poo). You have a small bowel and a large bowel. The large bowel is made up of the colon and rectum. The walls of your bowel have layers. The inner layers take in (absorb) nutrients from food and the outer layers help to move food through the bowel and waste out of the body.

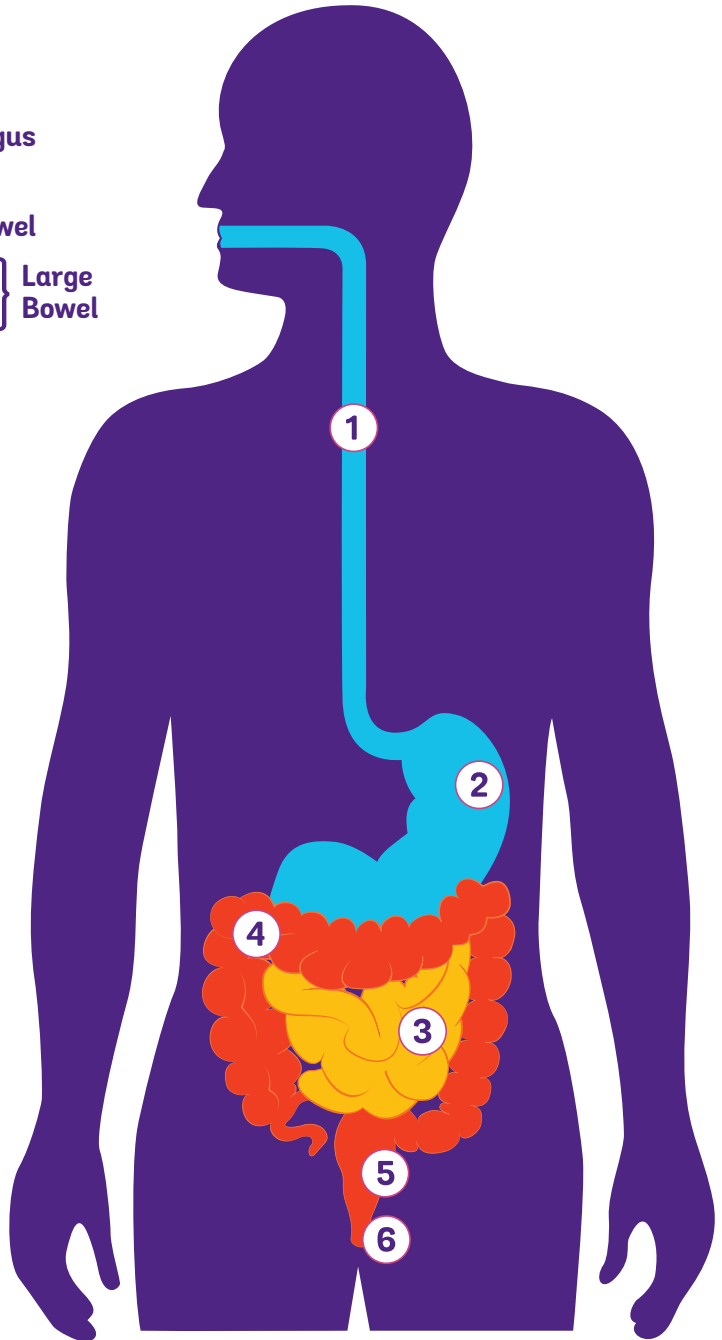
The inflammation in Crohn's and Colitis affects how your body digests food, absorbs nutrients and gets rid of waste. This can cause watery poo and more frequent bowel movements.

BOWEL LAYERS

- Inner lining
- Middle layers
- Outer layer



- 1 Oesophagus
- 2 Stomach
- 3 Small Bowel
- 4 Colon } Large Bowel
- 5 Rectum } Large Bowel
- 6 Anus



Crohn's Disease

In Crohn's Disease, inflammation can be anywhere in the gut from the mouth to the anus – but it's most common in the small bowel and colon. The areas of inflammation are often patchy, with normal gut in between. All layers of the lining of the bowel can be inflamed.

If your child has Crohn's in their colon, it's called Crohn's Colitis – this is a type of Crohn's Disease.

Ulcerative Colitis

Ulcerative Colitis is inflammation in the large bowel, which can be anywhere from the colon to the anus. Only the inner layer of the bowel (mucosa) is inflamed and tiny ulcers develop on its surface.

When we refer to Colitis in this booklet, we mean Ulcerative Colitis.

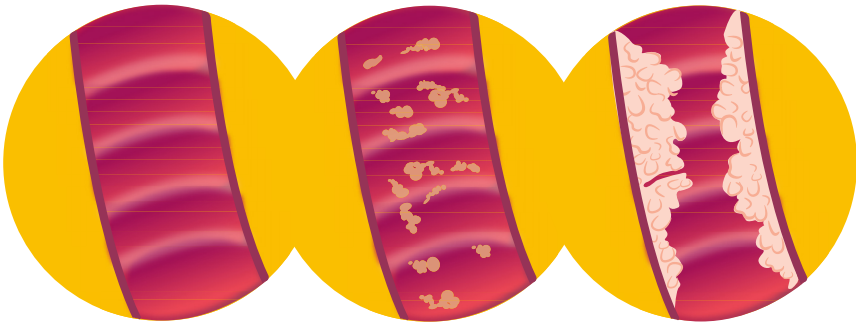
“

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, living with Colitis

Uncertain diagnosis

If your child is diagnosed with Indeterminate Colitis or IBDU it's not certain whether they have Crohn's or Colitis.



Healthy intestine

Ulcerative Colitis

Crohn's Disease



Symptoms

Everyone experiences Crohn's and Colitis differently.

When symptoms are active it's known as a relapse or a flare-up. There may be times when your child has active disease without showing any symptoms. Their IBD team will regularly check for this by looking for inflammation in their blood and poo. See the section **Tests**.

Your child may have:

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

Some children may also develop complications. These are more common in children with Crohn's, but in rare circumstances can occur in Colitis:

- **Abscesses** – collections of pus that can become swollen and painful. They are often around the anus and can cause a fever or lead to a fistula.
- **Fistulas** – narrow tunnels or passageways that form between the gut and another organ. In perianal Crohn's (Crohn's in the area around the anus) fistulas start inside the anus and connect to the skin outside the anus. You might be able to see the end of the fistula – it looks like a small hole in the skin and may leak pus or poo. They are often sore and painful. Medication and/or surgery will be used to treat fistulas.

- **Skin tags** – small growths around the anus that are sometimes mistaken for piles (haemorrhoids).

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



PRACTICAL TIPS

Managing tiredness and fatigue

Fatigue is an overwhelming sense of tiredness, lack of energy and feeling of exhaustion that doesn't go away after rest or sleep. Fatigue can be difficult to manage in children attending school, and extra-curricular and social activities. Speak to your child's doctor, as inflammation or low levels of some nutrients can be the cause of fatigue – your child's doctor may be able to prescribe supplements.

Sometimes it's difficult to know what's causing fatigue. Your child may need to take more time out, prioritise their time and learn that it's ok to say no. For other ways to help manage fatigue, see our information and new animation on **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. ”

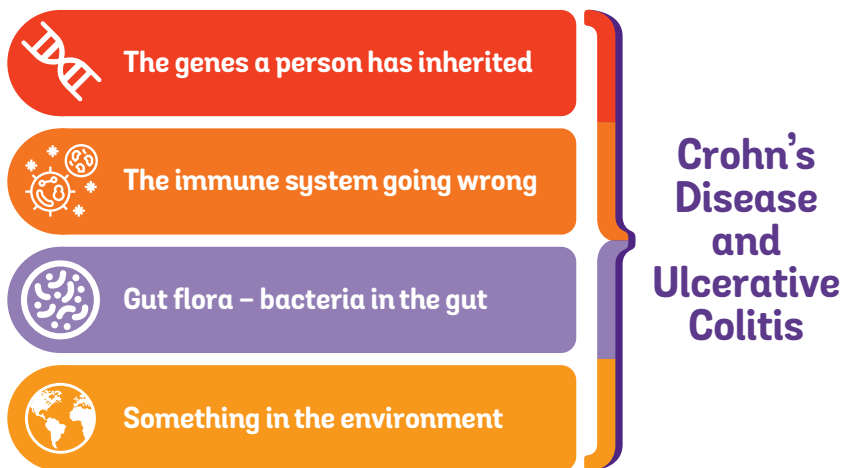
Ruth, mother to **Evie**, age 11, living with Crohn's Disease

Causes of Crohn's and Colitis

Crohn's and Colitis happen when the body's immune system goes wrong. Usually, the immune system protects the body. In Crohn's and Colitis, the immune system starts attacking the body.

We don't know why the immune system attacks the body. It's probably caused by a mix of genes and something in the environment (like germs, diet or stress).

There's nothing you could have done differently that would have prevented your child from developing Crohn's or Colitis.



Do Crohn's and Colitis run in families?

There's not always a family connection, but your risk of developing Crohn's or Colitis is higher if you have a family member with one of the conditions. It's hard to put a number on this risk, but research has shown:

- A family history is a stronger risk factor for developing Crohn's than it is for Colitis.
- The risk is higher when you are young, and reduces as you age.
- You could develop either condition, but you're more likely to develop the same condition as your family member.
- The risk is higher if you have two or more close relatives with Crohn's or Colitis.
- A family history is more common in some ethnic groups, for example, in Europeans compared to South Asians.

Most people with a family history of Crohn's or Colitis will not develop the one of the conditions.

Other parts of the body

Symptoms in other parts of the body are common. Some parents notice these before their child develops any gut symptoms. Your child's IBD team might use the term extra-intestinal manifestation (EIM) when talking about some of these conditions.

Bones and growth

Children with Crohn's or Colitis may grow more slowly or not grow as tall as other children. They may start puberty later or have weaker bones. This can be caused by their ongoing inflammation, poor nutrient absorption through their gut, and some treatments including steroids. Your child's doctor will consider all of this when planning their treatment options – they'll want to make sure your child's condition is controlled, while also giving them the best chance to grow and develop as they should.

Joints

Your child might have swelling and pain in their joints, known as arthritis. This usually improves as your child has treatment for their condition. For more details, see our information on [Joints](#).

Mouth

Some children develop mouth ulcers, sore gums, swollen lips or painful cracks in the corners of their mouth. This is more common in children with Crohn's and is sometimes called oral Crohn's. Mouth sores should get better as your child is treated for their Crohn's or Colitis. Your child's doctor may prescribe a medicated cream, gel or mouthwash to help. There's also some evidence that a diet free from cinnamon and benzoates may help oral Crohn's. Speak to a paediatric dietician before changing your child's diet.

Eyes

A small number of children develop red, irritated eyes that will usually get better as they are treated for Crohn's or Colitis.

Speak to an eye specialist or your child's doctor if you notice this, as very occasionally more serious eye problems can occur.

Skin

Skin rashes sometimes come on at the start of a flare-up or could be a side effect of some medicines. One type of rash, erythema nodosum, can cause small painful red patches on the shins. Skin rashes should go as your child is treated for Crohn's or Colitis. Speak to your child's IBD team if you notice a rash or skin problems.

Hair

Losing more hair than usual is common in Crohn's or Colitis. This type of hair loss is called telogen effluvium – it can be triggered by many things, including severe flares, poor nutrition, iron and zinc deficiencies, some medicines and surgery. Hair loss often happens months after the trigger, so it may not be obvious what's caused it. Your child shouldn't stop taking a medicine unless their doctor has said they should. Their hair will usually grow back completely as they get better. If your child is losing more hair than usual, speak to their IBD team to check what might be causing it.

Liver

Crohn's and Colitis can occasionally affect the liver. Your child will have regular blood tests to check for liver problems. Some medicines used to treat Crohn's and Colitis, including azathioprine and methotrexate, can also affect the liver. Changes in treatment can help to reduce this type of complication.

“

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, living with Crohn's Disease



PRACTICAL TIPS

Signs of a flare-up

Flare-ups can come on suddenly, without an obvious trigger. If your child becomes unwell again, it doesn't mean you've done anything wrong.

Your child may show different symptoms during a flare-up than when they were first diagnosed. Contact your child's IBD team if they have a persistent tummy ache, fever, vomiting, diarrhoea, blood in their poo, weight loss or general ill health, or if you're concerned in any way.

Work with your child's IBD team to create a flare plan – so you know exactly what to do, who to contact and how to contact them if you think your child is developing a flare-up. Some hospitals have an advice line where you can speak directly to an IBD nurse, others may have a phone number to reach the team secretary.

For some children, stress may be a trigger for Crohn's or Colitis symptoms. If you know your child will be going through a stressful time, such as changing schools or taking exams, they may need a bit of extra support. See the section **Supporting your child** for ways you can help to reduce stress.

Not all children will show symptoms when they're having a flare-up. It's important that your child has regular check-ups with their IBD team so their blood and poo can be tested to make sure their condition is under control.

Encouraging your child to follow their treatment plan and take their medicines is the most important thing you can do to help prevent a flare-up. See the section **Encouraging your child to take their medicines**.

Risk of cancer

Crohn's and Colitis can increase the risk of bowel cancer in some people – but this risk is still small. The risk only increases when you've had Crohn's or Colitis affecting most of the large bowel for more than 8–10 years, which means bowel cancer is rare in children. People with an increased risk of bowel cancer will have regular colonoscopies to check for the early warning signs. Find out more in our information on **Bowel Cancer Risk**.

In very rare circumstances, some medicines for Crohn's and Colitis can increase the risk of other cancers. The risk is very small and the benefits of taking the medicines will most often outweigh the possible adverse effects. Check the information leaflet in the medicine pack for precautions you can take to reduce this risk. For example, children taking azathioprine should always wear a high protection sunscreen, as there's a slightly increased risk of skin cancer.





TESTS AND TREATMENTS

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TESTS AND TREATMENTS

Tests

Your child will need a few different tests to find out if they have Crohn's or Colitis and to monitor their condition. Your child's GP will usually refer them to the children's (paediatric) unit of a hospital where they'll be seen by a paediatric gastroenterologist – a children's specialist doctor in gut diseases.



Blood and stool tests

Your child will usually have these tests first, to look for inflammation and anaemia (a reduced number of red blood cells) and to rule out infection. These tests will also be used to monitor your child's condition and check they're in remission.



Endoscopy

Doctors will use endoscopy, a tiny camera on a long flexible tube, to look closely at the lining of your child's gut. Endoscopy takes place in the children's gastroenterology unit of a hospital.

- If the tube goes through their mouth, it's called a gastroscopy (or upper gastrointestinal endoscopy). The doctor will look at their mouth, stomach and small bowel.
- If the tube goes through their bottom, it's called a colonoscopy or sigmoidoscopy. The doctor will look at their large bowel (rectum and colon) and the end of the small bowel (colonoscopy only).

“

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, living with Colitis

The doctor will also take tiny pieces of the lining of their gut (tissue biopsy) to check under a microscope. They'll also take photos to add to your child's medical records.

Younger children will have a general anaesthetic (medication

that's used to send them to sleep) during an endoscopy. Older children may be offered heavy sedation to keep them relaxed and comfortable, instead of a general anaesthetic.

If your child is having a colonoscopy, they may need to eat low fibre or liquid diet two days before the test. They'll also have to take a laxative to clear their bowel. Many children find this the most uncomfortable part of the test. Talk this through with the doctor or nurses, so you and your child know what to expect.

“

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, living with Ulcerative Colitis



MRI

MRI (magnetic resonance imaging) is commonly used to look at the small bowel in children. It has the advantage of not exposing children to x-rays – it instead uses magnets to build a 3D image of the body.



Barium meal and follow through

Your child will drink a thick liquid (barium) to dye their bowel so it shows up clearly on an x-ray.



Capsule endoscopy

Your child will swallow a capsule that sends photos of their bowel to an external recorder carried in a small bag. The capsule is about the size of a large jelly bean and will pass out in their poo.



Ultrasound and CT scans

Sometimes other scans are used to look at your child's bowel, including:

- Ultrasound, which is similar to that used in pregnancy.
- CT (computed tomography), which uses x-rays to create images of the body.

For more details, see our information on **Tests and Investigations**.



PRACTICAL TIPS

Managing days at the hospital

There are some things you can do to help make days at the hospital as stress free and fun as possible:

- Leave early – allow extra time for any disruptions to your journey, such as the bus not turning up or traffic. If you're driving, give yourself enough time to find parking.
- Expect lots of waiting around – take things to keep your child entertained, such as books and games, or download their favourite film or TV shows to watch.
- It might not be easy to leave the ward to go to the shop or restaurant, so take your own snacks and drinks.
- For extra hints and tips for children and parents, see the 'Children Coming to Hospital: My Hospital Experience' animation and information leaflets at edgehill.ac.uk/childrencomingtohospital

Treatments

Crohn's and Colitis affect everyone differently, but the aim of treatment is to make your child feel better and keep their condition (symptoms and inflammation) under control (remission). There are several types of treatment – these may be used one after another, or at the same time (in combination):

- Liquid diets (also known as enteral feeding or nutritional therapy).
- Medicines (drugs).
- Surgery.



There were times that the liquid diet 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, living with Crohn's Disease



Liquid diet (enteral feeding)

Children with Crohn's will usually be treated with an exclusive liquid diet. Your child will drink a specially prepared liquid 'food', such as Modulen IBD or Ensure, instead of normal food, for 6-8 weeks. These products are easily digested and provide all the nutrients needed for your child to grow properly. Ulcerative Colitis can't be treated with a liquid diet, although nutritional drinks are sometimes recommended to give children extra energy (calories) for growth.

You can get the liquid diets from your local pharmacy with a prescription. They usually come as a powder that you make up into a drink with

water. Most are available in different flavours, or you're able to add flavourings to them, and you might be able to get trial packs. Some brands also come in ready-to-drink cartons.

The drinks should be spread out through the day. If your child has difficulty drinking the large volume of liquid, they may find the diet easier to take through a nasogastric feeding tube (a fine tube passed through the nose into the stomach). It's worth trying to find a flavour or type of liquid food that your child likes without the need for a nasogastric tube. Your child's dietitian or IBD team should be able to help with this.

A nasogastric tube shouldn't stop your child going to school, college or taking part in all their usual activities. Some children feel self-conscious about the tube so it could help to speak to their

“

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, living with Crohn's Disease

teachers before they get the tube. You can give the feed at a time that suits your child's daily routine. Some can even be given overnight while your child is sleeping.

Talk to your child before they start the liquid diet to find out what they'd prefer to do during family mealtimes – some children prefer to do something else rather than sit with the family. This should be their decision, so they don't feel they're being excluded from normal family life. Also discuss how they'd like to handle meals at school.

Most children begin to feel better after a few days on the liquid 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. Your child may be able to have other drinks but check with their doctor first. If your child is still hungry contact their IBD team or dietician as they may need some extra calories. Foods are gradually re-introduced over several weeks and your child's IBD team will advise you on how to do this. Your child may find it hard not to have solid foods for such a long time. Try to remain positive and encouraging because this is a very effective treatment.

Your child may have to go on an exclusive liquid diet again during follow-up treatment to improve their growth and help keep their condition under control.

“
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, living with Crohn's Disease





Diet and food

Eating with Crohn's and Colitis is different for everyone. You'll probably come across lots of diets that claim to treat the conditions – but apart from a liquid diet for Crohn's, no diet has been proven to treat children with Crohn's or Colitis.

Some people do find certain foods trigger their symptoms, but it's different for everyone. For example, some children feel better if they avoid spicy food or drinking large amounts of milk. If you think a particular food is upsetting your child, keep a food diary to record what they've eaten and their symptoms after. It may be sensible for your child to avoid eating certain foods that upset them, but always discuss this with their dietician or doctor first.

Your child shouldn't need to take any additional vitamins or minerals, unless told by their doctor. Their doctor will monitor levels in their blood, such as vitamin D and iron, and will prescribe supplements if they are low. Above all, it's important that your child eats a healthy balanced diet when they can, as this is essential for their continued growth and development. Talk to your child's dietician or doctor before making any changes to their diet.

Our information on **Food** has more details on healthy eating with Crohn's or Colitis and suggests ways that diet may help to manage certain symptoms. Your child's IBD team may also be able refer you to speak to a nutritionist or dietitian.

“

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, living with Ulcerative Colitis



PRACTICAL TIPS

Encouraging your child to eat

Children with Crohn's or Colitis are often thin or underweight. Your child may lose interest in food if they're having a flare-up or if eating makes their symptoms worse. It can be difficult for a child with Crohn's or Colitis to eat enough to reach their ideal weight, especially during the growth spurt at puberty. Your child's doctor may recommend nutritional drinks to top-up their calories.

Although this lack of interest in food can be both worrying and frustrating, there are some things you can try:

- Keep calm and try not to insist that they 'finish everything on the plate'. It's their condition that's making them unable to eat, not the cooking.
- Relax your rules about food and allow your child to eat snacks and calorie-rich foods, at least some of the time. If you're worried about lost nutrients, ask your child's IBD team for advice.
- Try offering smaller meals and snacks more often during the day, or, if your child is older, encourage them to make their own when they feel like it.

As your child's treatment starts to work, it should also help their growth. But, if you're worried, talk to your child's doctor and they may refer your child to an endocrinologist (growth specialist).

Medicines

The medicines (drugs) used to treat Crohn's and Colitis aim to stop inflammation and reduce the chance of a flare-up. These medicines sometimes cause unwanted side effects, but they will be used carefully and in the smallest doses needed to help your child feel better. Your child's IBD team will monitor their health closely and can explain how the medicine will work. Older children may find it helpful to talk to their IBD team themselves. Encourage

them to ask questions about what to expect and how the medicine may affect them.

There are four main types of medicine used to treat Crohn's and Colitis in children. Your child may have to take just one or a combination of medicines at the same time.

“

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, living with IBD Unclassified



Aminosalicylates (also known as 5-ASAs), such as sulfasalazine and mesalazine, are used to treat Colitis. Your child may need to take them every day for several years, even when they're well. If your child has inflammation in the lower part of their colon or rectum, they may be given the drug as an enema or suppository – a medicine that goes into their bottom (anus). Your child may find this unpleasant, but it is important that the medicine can get straight to where it is needed to make them feel better.



Corticosteroids (steroids), such as prednisolone and budesonide, are used to treat flare-ups and can act very quickly to make your child feel better. However, they can also have unwanted side effects, for example, your child's face may temporarily become rounder (known as moon face), and they may become very hungry and put weight on quickly. In teenagers, acne can get worse. Steroids can also cause problems with sleeping, and some children become irritable, moody, or revert to earlier behaviours such as temper tantrums. Steroids also affect growth, so doctors will try to keep the number of steroid courses and the total dose to a minimum. The side effects are reduced as the dose of steroids is reduced - this must be done gradually rather than just stopping.

Steroids given as enemas or suppositories cause fewer side effects as less of the medicine is absorbed into the body.

Anyone treating your child for another illness, or if they have an accident, will need to know about their steroid treatment. Your child could carry a 'Steroid Card' (available from pharmacists) or wear an emergency bracelet, like the ones made by **MedicAlert**. See the section **Other organisations** for more information.

Corticosteroids are different to the anabolic steroids used by athletes to improve their performance.



Immunosuppressants,

such as azathioprine and mercaptopurine, dampen down the immune response and reduce inflammation.

Immunosuppressants act slowly and it can take 8-16 weeks for the medicine to have an effect on the body. At the beginning of treatment your child may have nausea, vomiting or a loss of appetite. It's important that your child has regular blood tests while taking immunosuppressants as they can sometimes stop the body from making enough blood cells. If this happens, the dose can be adjusted, but sometimes the medicine must be stopped.

If your child has too many side effects from azathioprine or mercaptopurine, or if these medicines aren't working, they may be given a different immunosuppressant, such as methotrexate.



Biologic medicines, such as adalimumab and infliximab, work with the immune system to block the ongoing inflammation. Your child may be given a biologic medicine if they're very unwell, or if other treatments haven't made their symptoms better. Infliximab is given through a drip in the arm (intravenous infusion) in hospital, while adalimumab is injected under the skin of the tummy or leg (subcutaneously) at home. If these medicines don't help your child to get better, or

“

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, living with Ulcerative Colitis

they're causing bad side effects, your child may be able to try a different biologic medicine or, in some cases, access a different medicine through a clinical trial. Speak to your child's doctor to find out if there are any medicines available through clinical trials.

You can find out more in our individual drug treatment information: **Adalimumab, Aminosaliclates (5-ASAs), Azathioprine, Biologic medicines, Infliximab, Methotrexate, and Steroids.**



PRACTICAL TIPS

Encouraging your child to take their medicines

Your child needs to take their medicines as told by their IBD team – this is important to keep them well and prevent flare-ups. This can be difficult for children – some may rebel whereas others may simply forget. You could try some of the following:

- Make it part of their routine – so taking their medicine becomes just like brushing their teeth or having a bath.
- If it's difficult to manage lots of different medicines, try setting alarm reminders on your (or your child's) phone.
- Keep a diary of unpleasant side effects and speak to your child's IBD team about possible ways to reduce these.
- If your younger child is struggling to take medicines, you could use a reward chart.
- Get older children involved in managing their condition. Encourage them to ask questions and have a say in decisions about their treatment.
- Try to stay positive and encouraging. Talk to your child to understand what the underlying issues are. Your child's IBD team are there to help – speak to them for extra support with taking medicines.

Points to remember about taking medicines

- Try to be patient and encouraging. Finding the right combination of medicines that work for your child can be a long and sometimes frustrating process. Crohn's and Colitis can change over time – so your child's treatment may need to change over time. It may also take time to see the benefits of a change in treatment.
- There may be times when managing the side effects of medicines feels just as challenging as managing the condition itself. If your child is unwell and you're not sure whether it's a side effect of a medicine or symptom of the condition, speak to your child's IBD team. They'll be able to suggest ways to help reduce the side effects. If you think your child is having an allergic reaction to a medicine, speak to a doctor immediately.
- Your child will likely have regular check-ups at the hospital to monitor their treatment. Use this time to share any side effects or ask any questions you have – see the section **Making the most of the time with your child's IBD team** for tips.
- Steroids, immunosuppressants and biologic medicines can reduce your child's ability to fight infections. Some infections, like chicken pox and measles, can be serious, so speak to child's doctor if they come into contact with someone with an infection (particularly if your child hasn't been vaccinated).
- Immunosuppressants and biologic medicines can also increase sensitivity to sunlight. Make sure your child is properly protected from the sun by covering them up, keeping them in the shade and using a high protection sunscreen.
- Speak to your child's doctor before giving them any other medicines as there could be an interaction with the medicine they're taking for Crohn's or Colitis. This includes over-the-counter medicines (medicines you buy yourself) and any herbal, complementary or alternative treatments.

- Your child shouldn't stop taking their medicines unless their doctor has said it's ok to do so. If your child is struggling with their medicines, see the section **Encouraging your child to take their medicines**.



Surgery

The thought of your child having surgery can be worrying, but surgery is an important treatment option that can help your child feel well again. Surgery may be an option if your child isn't getting better with medicines, if they have very severe disease or if they have strictures or fissures associated with Crohn's. Your child's gastroenterologist will refer you to a surgeon to explain what will happen and give you a chance to talk through any concerns. Many of these operations can be performed by keyhole surgery (laparoscopy), a type of surgery where only small cuts are made to access the inside of the body. There's less pain and a faster recovery after keyhole surgery. Planned surgery should only happen after careful discussion with you, your child and their IBD team.

Strictures

A stricture is when the bowel wall thickens and the space inside becomes very narrow. Strictures make it hard for food to pass through the bowel and can be painful, particularly when eating. Surgery may be needed to remove the affected area, widen it, or, less commonly, stretch (dilate) it.

“

Today I feel like I've got control over my body. That's amazing. Before the operation, my body had control over me. ”

Aleesha, diagnosed with Ulcerative Colitis during her A-levels and living with a stoma since the age of 18. Read Aleesha's story in **The Unstoppables: Young People**

Fistulas

A fistula is a narrow tunnel or passageway that forms between the bowel and another organ or the skin around the anus (see the section **Symptoms**). Surgery may be needed if a fistula doesn't get better with medicines. Placing a 'seton' is the most common surgical procedure for fistulas around the anus. A seton is like a thin, loose, rubber band that sits in the fistula tunnel allowing it to heal more effectively. It also prevents the build-up of pus, which could cause an infection and/or an abscess. See our information on [Living with a Fistula](#).

Ileostomy/colostomy

Children with severe Crohn's or Colitis may need surgery to remove the part of their bowel that is making them unwell. In this operation, the end of their bowel is connected to the outside of their tummy (abdomen) and their poo goes straight into a bag. If the ileum (part of the small bowel) is connected, it's called an ileostomy. If it's the colon (part of the large bowel), it's called a colostomy.

Both types of opening are called a stoma and the bag is known as a stoma bag. A stoma may be temporary or permanent. Many children find having a stoma is easier than feeling unwell with Crohn's or Colitis – they can continue their lives as normal, enjoying sports and other activities, including swimming. Many hospitals have a specialist stoma team to support you and your child during and after the surgery. You can find more in our information [Living with a Stoma](#).

For some children the stoma will be temporary – they may have additional operations to make a pouch from their small bowel (called an ileo-anal pouch) that connects to their anus. They will then pass poo out of their anus and won't need a stoma bag. This surgery may happen a number of years later. It can have good outcomes, but there can also be unwanted side effects, for

example, reducing fertility in women. There are risks with all types of surgery, so speak to your child's IBD team if you are worried.

See our information on **Surgery for Crohn's Disease** and **Surgery for Ulcerative Colitis**.



Vaccinations

It's important that your child has routine vaccinations given by their GP or at school. These include the 3-in-1 teenage booster (tetanus, diphtheria and polio), the MenACWY vaccine (meningitis) and the HPV (human papillomavirus) vaccine. These vaccines are usually safe for children with Crohn's or Colitis, but always check with your child's IBD team first.

Live vaccines

Your child shouldn't have live vaccines if they're taking certain steroids, immunosuppressants or biologic medicines because these medicines weaken the immune system. They may have to wait 3-6 months after they stop taking these medicines before they can have a live vaccine.

Live vaccines include the MMR (measles, mumps, and rubella), yellow fever, BCG (tuberculosis), chickenpox (varicella) and the nasal spray flu vaccine. If someone living with your child is due to have a live vaccine, ask their IBD team if they need to take any special precautions.



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. ”

Rachel, mother to **Thomas**, age 12, living with Crohn's Disease

Flu vaccination

All children with Crohn's or Colitis should have a flu vaccination every year. Most children up to the age of 10 will be offered this through their school and it's likely they'll be offered the nasal

spray. The nasal spray is a live vaccine, so can't be given to children on certain steroids, immunosuppressants or biologic medicines. Your child can have the annual flu jab (injection) instead as this is not a live vaccine.

Travel vaccinations

Your child (and the rest of your family) may need extra vaccinations if you're planning to travel outside the UK. Speak to your child's GP or a private travel clinic at least 8 weeks before you travel. Some travel vaccinations, including yellow fever, are live vaccines. Your child may not be able to have live vaccines if they're taking a medicine that weakens their immune system (see the section **Live vaccines**). You can also ask your child's GP more general advice about travel health, such as protection against malaria.



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SUPPORTING YOUR CHILD

Helping your child cope with their diagnosis

It's important that you take care of your child's emotional and mental health as well as their physical health. Your child's mental health could have an impact on their sleep, physical symptoms like pain and fatigue, and whether they take their medicines properly. There are some things you can try to help your child cope with their condition:

Be as open as possible

Your child, like you, will probably need time to get used to their diagnosis. Explain what's happening in words your child understands so they don't imagine other things that could happen. Be as honest as possible. If something's going to hurt, say so – but also explain that it'll help them feel better in the long run. For example, you might say 'the blood test is a short sharp scratch' and help them count down from 10 until it is over.

“

Harry knows all of the possibilities and consequences, like that one day he might need to have surgery. Even though he's only 11, this openness has made him quite pragmatic and he doesn't fear that possibility. ”

Rob, father to **Harry**, age 11, living with Crohn's Disease

Reassure them

Some symptoms, like blood in their poo, might be scary for children, or some may even try to hide their symptoms. They may get upset about having to go through uncomfortable tests, take unpleasant tasting medicines or be seen with 'embarrassing' treatment aids, such as a feeding tube. Acknowledge their upset – it's ok not to be ok and to express unhappiness. Remind and reassure them that flare-ups are temporary, and that they'll feel better after treatment. Let them know it's not their fault. This isn't happening because of anything they've done.

Focus on the positive

Focus on what your child can do rather than what they can't. Break tasks into manageable steps and celebrate each success along the way. If possible, try not to restrict family life because of your child's condition. If your child has a relapse, you may have to postpone certain activities or outings until they feel better. Reassure them that they won't feel the same way forever. Encourage them to make the most of the times when they're feeling healthy and not to use their condition as an excuse for not doing things. Perhaps show them examples of people who have flourished with Crohn's or Colitis, like the magician Dynamo, the silver medal-winning Olympic swimmer Siobhan-Marie O'Connor, Strictly Dancer Amy Dowden, or former Premier League footballer Darren Fletcher.

“

I was diagnosed with Crohn's Disease when I was 19 years old, although I started suffering with the symptoms from the age of 12. Mum and Dad sacrificed their spare time taking me to classes and shows. I have always been driven to win, so Crohn's wasn't going to hold me back. ”

Amy Dowden, professional dancer on Strictly Come Dancing

Help them find their 'flare hobby'

If your child can find a happy way to pass the time during a flare, it'll help soften the blow – they could try reading a book (or listening to an audio version), playing computer games or learning a new craft or skill.

Get them involved

Encourage your child to ask questions and describe how they're feeling. Show them simple ways to manage their condition, like taking more responsibility for managing their own medicines. Give them choices where possible, for example, which arm they'd prefer the needle in.

Help them see the funny side

At times, having a sense of humour could make your child feel better and help them realise that they don't have to feel embarrassed about their symptoms in front of you.

Meet other families

Children often feel less isolated if they can talk to others in a similar situation. You may be able to meet other families through the Crohn's & Colitis UK Local Networks and events based across the UK. Your child's IBD team may also be able to put you in touch with other local families.

Your child's emotional wellbeing

Your child will likely experience ups and downs, but there may be times you notice more worrying changes in their mood or behaviour. If you think your child could be experiencing stress, anxiety or depression, some signs to look out for are:

- Becoming withdrawn or isolated.
- Avoiding friends and social situations.
- Having trouble sleeping.
- Acting out at school or at home.

Encouraging your child to talk is the first step. They may find this difficult, so keep trying and stay positive and encouraging. Choose a time when there are few distractions. Teenagers may be more likely to open up if you're side by side, for example, sat in the car or going for a walk together, whereas younger children may find it easier to draw what's worrying them. Your child may find it easier to talk to another trusted adult, such as a close family member, their IBD nurse or their favourite teacher. Some schools may also offer pastoral care. By talking about their

“

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, living with Crohn's Disease



PRACTICAL TIPS

To help your child's emotional wellbeing, you could encourage them to:

- Write down how they feel or keep track of their mood in a mood diary. Teenagers could try the NHS recommended **MeeTwo app** – it provides a safe space for them to open up and get positive advice and support from their peers. All posts and replies are checked to make sure only positive feedback is published.
- Practice deep breathing, meditation or yoga. Apps like **Headspace** or **Smiling Mind**, or **Cosmic Kids Yoga** for young children, can guide them through these techniques.
- Go for a walk, or take part in sports or exercises they enjoy – or try a new one.
- Try painting, drawing or colouring.
- Do what makes them feel relaxed, like watching a film, reading a book or playing a game.

worries you can help your child see things differently and share ways to help them cope.

If you're concerned about your child's emotional wellbeing, talking to a counsellor might help. Check if your child's IBD team includes a counsellor or clinical psychologist, or ask if they can refer you to one. Your GP practice or child's school may also have a counsellor on the staff. In the meantime, your child may be able to speak to a counsellor through a helpline such as **Childline**.

“

We've put a lot of focus on making home a calm, stress free and fun space. Whether it be a good day or a difficult IBD day, we all feel equally comfortable and relaxed. I think this has contributed to reducing the severity of symptoms and has meant that we all respond to changes in a calm way. ”

Rob, father to **Harry**, age 11, living with Crohn's Disease

Young Minds runs a helpline for parents and adults worried about a child's mental health. Contact details can be found in the section **Other organisations** at the back of this booklet. Our information on **Mental health and wellbeing** has more about talking therapies, how to get psychological support and how it might help people with Crohn's or Colitis.

Bullying

The signs of bullying in children can be similar to those associated with stress, anxiety or depression, but may also include:

- Worrying about school or skipping school.
- Suddenly doing less well at school.

If you think your child is being bullied, try some of the steps above to encourage them to open up to you. Understandably, you may feel angry or upset by this, but remain calm and reassuring for your child. Get in touch with your child's teacher and make sure your child knows what's going on and what they should do. The charity **Family Lives** has information on what steps to take if your child is being bullied and offers a helpline and email service for parents. See **Other organisations** for details.

Looking after your own emotional wellbeing is important too. If child's IBD team includes a counsellor or clinical psychologist, they may offer support to other family members as well, such as parents and siblings. For more on taking care of yourself, see the section **Support for you**.

How can I help my child cope with the stress of exams?

Some children may find stress makes their symptoms worse. Offer your child extra support and make sure they don't overdo their exam preparation. They need to find a balance between doing enough studying to do well and staying well. Having regular breaks in revision is important. Make sure your child also spends time relaxing and having fun. Some of the

suggestions in the section **Your child's emotional wellbeing** may also help your child cope with stress during exam time.

Let your child's school know that exams can be difficult for children with an unpredictable condition like Crohn's or Colitis. Schools and colleges may be able to make special arrangements, such as postponing internal exams or dates for handing in assignments. Children with Crohns or Colitis may be able to do their exams in separate rooms so they can access toilets more easily, or be allowed extra time in exams. Speak to your child's IBD team if the school needs any extra information or letters about their condition. A child with Crohn's or Colitis may be covered by the Equality Act 2010. This means the school has a responsibility to make reasonable adjustments to prevent the child being placed at a disadvantage. **Disability Rights UK** provide more information on education and students with disabilities.

Resources for children and young people

It can be hard explaining Crohn's and Colitis to children in a way they'll understand. We've developed some resources to help start conversations.

The Unstoppables: Young People

The children and young people in this booklet all have Crohn's or Colitis. Together, we helped them get through the tough times and start feeling like themselves again – here they share their stories and advice for other young people.

Meet our Crohn's and Colitis cats

A colourfully illustrated story book and animation to help explain Crohn's and Colitis to children. You can watch the animation or order a printed copy for free from our website:

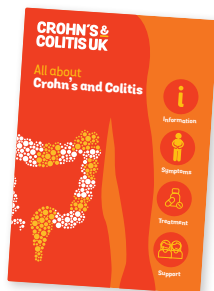
crohnsandcolitis.org.uk/cats



All about Crohn's and Colitis

This booklet has all the basics you need to know about Crohn's or Colitis if you're new to the condition. The easy-to-read format may make this a helpful resource for teenagers and young people.

crohnsandcolitis.org.uk/all-about



Transition: moving to adult care

A guide written with the help of other young people to help you prepare for your move to adult care.

crohnsandcolitis.org.uk/transition

'What are Crohn's and Colitis?' animation

A 2-minute animation explaining the basics of Crohn's and Colitis.

crohnsandcolitis.org.uk/about-crohns-and-colitis

It Takes Guts Talking Toolkit

Your child can create their own Talking Toolkit to help them find the words to talk about Crohn's and Colitis to their teachers and friends.

ittakesguts.org.uk/talking-toolkit

Young person films

Five young people highlight the challenges younger people with Crohn's and Colitis face, including school, leaving home for university and relationships and share their own ways of coping.

crohnsandcolitis.org.uk/young-person

16– 18 Student Membership

Students with Crohn's or Colitis aged between 16 – 18 years are eligible for free Crohn's & Colitis UK membership. To join, visit crohnsandcolitis.org.uk/membership

‘Telling my Friends’ animation

An animation about talking to friends, based on a research study with young people with Crohns or Colitis, funded by us.

sites.edgehill.ac.uk/cc/



Over The Wall Family Camps

Over The Wall offer free weekend activity camps for children and young people with health conditions and their families – they even offer camps for siblings of children with health conditions. Visit otw.org.uk

CICRA – Crohn’s In Childhood Research Association

CICRA are a charity dedicated to helping children with Crohn’s and Colitis live as normal a life as possible. Their website features useful information and videos about Crohn’s and Colitis for children and young people. See cicra.org/videos and cicra.org/what-is-ibd/childrens-area



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LIVING WITH CROHN'S AND COLITIS

Talking about your child's condition

Crohn's and Colitis are known as invisible illnesses. Your child might look fine on the outside even if they have painful or distressing symptoms. This can make it hard for people around them to know how unwell they are, but it's up to you and your child how much you tell friends and relatives outside the immediate family.

Negative reactions are more likely when people don't understand the condition. Being open and honest is usually the best way to combat any confusion or unfounded fears. It could help to talk to the parents of your child's friends – once you've checked that your child is happy with this. Other parents may be worried that your child's condition is infectious or be unsure of what your child can eat. They could be reluctant to mention it until you do. You'll probably find that most people are supportive once they know how they can help.

We know it can be difficult to talk about Crohn's and Colitis so we've created a new website with tools, tips and support for starting conversations. Visit ittakesguts.org.uk

“

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, living with IBD Unclassified



PRACTICAL TIPS

Key points to remember about Crohn's and Colitis

- Every child and young person experiences Crohn's or Colitis differently
- Inflammatory Bowel Disease is not the same as Irritable Bowel Syndrome
- Crohn's and Colitis are fluctuating and unpredictable
- Crohn's and Colitis are invisible illnesses
- Crohn's and Colitis are not contagious
- There is no known cure

School

School is a key part of your child's life and they should be encouraged to take part in as much as they can just like any other child. Some children may be tempted to use their illness as an excuse to stay off school unnecessarily. It's probably best to expect your child to attend school unless they're unwell.

Your child spends a lot of time at school, so it's important that their teachers know about their condition. Together you can create a plan to help manage their condition at school – your child's IBD team may also be able to help with this. Teachers and school staff are usually accepting and helpful once they understand what's 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, living with Crohn's Disease

Schools have a legal responsibility towards children with disabilities and medical needs under the Equality Act 2010, which may apply to a child with severe Crohn's or Colitis. See the **Disability Rights UK** factsheets for more information on this.

The charity **CICRA** provide lots of information about schools. You may find it helpful to give your child's school copies of their **Resources for schools** so staff know how best they can support your child.

What about my child's classmates?

Children vary in terms of how much they want their friends or other children at school to know about their condition. Some may appreciate a teacher explaining their condition to the class, others would find this highly distressing. Talk to your child about this before you speak to their teachers.

If your child is older, they could ask their friends (or their teachers) to live in their shoes for 24 hours, with our new app **In My Shoes with Crohn's or Colitis**. This is available to download from both the Apple and the Google Play app stores.

“

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, living with Ulcerative Colitis

“

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, living with Crohn's Disease

You could download the app together first, to see if it's something your child would like to share with their friends.

Sport and exercise

Sports and exercise are a big part of life for many children – and this should still be encouraged in children with Crohn's or Colitis. Exercise can have positive effects on mood, self-esteem, sleep quality and energy. There will probably be times when your child isn't well enough or they're too tired to take part in sports or exercise, and that's ok. Try to make the most of times when they feel well, and the times of the day when they have the most energy. If your child isn't very active, build up their activity levels gradually, even a little is better than nothing. Make it fun – you could even get the whole family involved. If you're not sure whether your child should take part in certain activities or sports, speak to their IBD team, and then rely on how they feel at the time.



RESEARCH FACT

In a study of Crohn's & Colitis UK members, 7 in 10 said that exercising made them feel better and 1 in 10 said that it helped their symptoms, weight control and improved their sleep.

Family holidays

There's no reason why you shouldn't be able to take family holidays – it might just take some extra planning. Our information on **Travel** covers things to consider before travelling, and includes travelling with a stoma and tips for staying well on holiday with Crohn's and Colitis, such as:

- Find out about insurance, vaccinations and malaria tablets before you book your holiday.

- Plan to take enough medicines to cover the whole time your child will be away, plus extra to cover any delays.
- Ask your child's doctor for a medical summary and take a copy of their contact details.
- Wear a sunflower lanyard. Major travel hubs in the UK are using the sunflower lanyard scheme to let staff know that someone is living with an invisible disability.
- If flying, tell the airline if your child has special dietary requirements and check if you can book a seat near the toilet.
- Pack your child's medicines and other medical supplies in your hand luggage – speak to the airline about any restrictions. It could also help to take an emergency travel kit with everything needed to clean up if they have an accident.
- Follow good standards of food and water hygiene while away, for example, drinking bottled rather than tap water.

It's important you have the right travel insurance because medical treatment abroad can be expensive – as can emergency travel back to the UK. Flare-ups are unpredictable, so it could be worth taking out insurance even if you only plan to holiday in the UK. Our information on **Insurance** has more details about travel insurance for people with Crohn's or Colitis.

“

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, living with Crohn's Disease

“

We always take out comprehensive travel insurance, as there have been 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, living with Ulcerative Colitis



PRACTICAL TIPS

Helping your child feel confident when out

Access to toilets can be a worry for people with Crohn's or Colitis, but there are a few things that can help give your child extra confidence when out and about:

- Carry an emergency kit containing wipes, disposal bags, and spare clothing – just in case.
- Become a member of Crohn's & Colitis UK and receive a 'Can't Wait Card' so your child can quickly and easily ask to use toilets.
- Get a RADAR key to open disabled toilets. You can get a RADAR key for free if you are a Crohn's & Colitis UK member, or you can buy one from **Disability Rights UK** – see the section **Other organisations**.
- If you're travelling by car, keep a small portable camping toilet in the boot.
- Make sure your child knows where the toilets are before they go on a long journey or to a new place. You can usually find this kind of information online.

Financial help

You may find that you're spending more on heating bills, laundry costs, special diets, taxi fares and lost days at work. Even if you don't consider your child to be disabled, Disability Living Allowance (DLA) can help to cover these extra costs. DLA is available for children under 16 who need more care or help than children of the same age without a medical condition. See our information on **Claiming Disability Living Allowance** to check if your child could be eligible and for information on how to apply. Our **Disability Benefit Service** can answer your questions about eligibility and help you to complete the application form. Call our Helpline on **0300 222 5700** to make an appointment.

Young people going to university or college may be able to apply for Disabled Students' Allowance (DSA). DSA can help meet the extra expenses that come with their condition, for example, the cost of en-suite accommodation.

Our information on **Finances** details other benefits, grants and help with health, housing and transport costs that could be available to families living with Crohn's or Colitis.

“

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, living with IBD Unclassified

Taking time off work

You could mention your child's condition to your employer, so they're already aware of your situation. Decide how much information you want to share with them. Check if your workplace has any policies in place for taking time off as they may offer more than the minimum required by law.

Unplanned time off

All permanent, temporary, full-time or part-time employees have the right to unpaid time off work to deal with unexpected events involving their child, for example, if their child is suddenly unwell and needs a day off school. It covers both mental and physical illnesses. There's no limit on how many times you can take unplanned time off, but it must be reasonable. Consider if anyone else can help or if other arrangements can be made. Your employer shouldn't make you rearrange your working hours to make up the time.

Planned time off

There's no legal right to time off if you knew about a situation beforehand, such as taking your child to a planned hospital appointment. Some employers may allow you to make up your hours at another time or use your annual leave. In some cases, you may be able to get parental leave.

Parental leave

Unpaid parental leave can be used to look after your child, for example, if you need to stay with them while they are in hospital. You must be an employee, have been in the company for at least a year and must have parental responsibility for your child. There are limits on how much parental leave you can take and how much notice you must give your employer. Check your workplace policy on parental leave.



Flexible working

There may be other options to consider with your employer, such as having flexible start and finish times or working from home. Employees can request flexible working if they've worked with the same employer for at least 26 weeks.

If you're unsure about your rights or think you're being treated unfairly by your employer, you can get free advice from your local **Citizens Advice** or the charity **Working Families** – details can be found in the section **Other organisations**.

Transition to adult services

It can be hard to learn to let go as your child grows older and becomes more independent – and if your child has Crohn's or Colitis, it can be even harder. It's important that your child is in control of their condition and their treatment by the time they leave home.

The hospital treating your child will also be encouraging them to take more responsibility as they reach their teenage years. This is 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 when a child turns 16, but sometimes it can be delayed until a little older. Each hospital manages transition differently – some have transition clinics for 16 - 19 year olds, others offer one or two joint appointments and some have a system of direct transfers. Your child should have an individual transition plan, made by them and their key worker (usually their IBD nurse). Ask your child's IBD team about their hospital's arrangements.

Help your child prepare for this. Let them take more control of their medicines. Let them meet their doctor or nurse alone, even it's just every now and again. Encourage them to think of and ask their own questions. You could sit down together a day or so before to help them make a list of things they want to say. This will help them develop independence and confidence for when they meet their new IBD team in the adult clinic.

Your child might find it helpful to read our information for teenagers going through the transition process:

Transition: moving to adult care.

“

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 **Emma**, age 11, living with Crohn's Disease

OTHER ORGANISATIONS

Other organisations

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OTHER ORGANISATIONS

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

Childline — childline.org.uk
Speak to a counsellor: 0800 1111

CICRA (Crohn's in Childhood Research Association) — cicra.org
020 8949 6209

Citizens Advice — citizensadvice.org.uk
03444 111 444

Disability Rights UK — disabilityrightsuk.org
Disabled Students Helpline: 0330 995 0414
Shop: 0203 687 0790

Family Lives — familylives.org.uk
Parent helpline: 0808 800 2222
askus@familylives.org.uk

IA (Ileostomy and Internal Pouch Support Group) — iasupport.org

Medic Alert — medicalert.org.uk

Over the Wall — otw.org.uk

PINNT (Patients on Intravenous and Nasogastric Nutrition Therapy)
— pinnt.com

Young Minds — youngminds.org.uk
Parent helpline: 0808 802 5544

Working Families — workingfamilies.org.uk
Helpline: 0300 012 0312
advice@workingfamilies.org.uk

Learn about Crohn's and Colitis in our new children's story. Watch the video or get the book from crohnsandcolitis.org.uk/cats



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BECOME A MEMBER

As a member of Crohn's & Colitis UK, you'll become part of a powerful community fighting for change.

You'll receive exclusive information and updates, a Can't Wait Card and RADAR Key to help with toilet access, and much more.

Join us today. Visit crohnsandcolitis.org.uk/membership or call 01727 734465



CROHN'S & COLITIS UK



We're here for you whenever you need us. Our award-winning publications have the information to help you and your child manage their condition. We cover a range of topics, from medicines to coping with symptoms and school. We'll help you find answers, access support and take control.

Publications are available for free at crohnsandcolitis.org.uk/publications

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Helpline

Our confidential helpline offers information and support for anyone affected by Crohn's and Colitis.

We can help you:

- Learn more about Crohn's and Colitis treatment, symptoms, tests, diet and more.
- Find support.
- Access disability benefits.

We can also help you to find support from others living with the condition.

Call us on **0300 222 5700**

Email us at helpline@crohnsandcolitis.org.uk

Speak to us on Live Chat at crohnsandcolitis.org.uk/livechat