

SUPPORTING YOUR CHILD WITH CROHN'S OR COLITIS

If your child has been diagnosed with [Crohn's](#) or [Colitis](#), it's natural to feel worried about what this could mean for them and your family. But there's lots you can do to help your child live life to the fullest.

This information looks at:

- How Crohn's or Colitis might affect your child
- The treatments your child might be offered
- Tips for everyday life
- Things you can do to help your child
- Ways to look after yourself and your own wellbeing

The information is aimed at parents of children under 16, but a lot will still be relevant if your child is older.

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KEY FACTS ABOUT SUPPORTING A CHILD WITH CROHN'S OR COLITIS

- Crohn's and Colitis are the two main types of Inflammatory Bowel Disease (IBD). They are not the same as Irritable Bowel Syndrome (IBS).
- Crohn's and Colitis can cause painful ulcers and inflammation in the gut. They can affect parts of the body outside the gut too, and cause extreme tiredness known as fatigue.
- Crohn's and Colitis are lifelong conditions, which means your child will always have it. But that does not mean they will always feel unwell.
- Crohn's and Colitis affect everyone differently, and symptoms can be unpredictable.
- Treatment varies from person to person. Your child may have a liquid diet or medicines. Some children may need surgery.
- You may need to be flexible with any plans you make in case your child becomes unwell at short notice.
- It's important to look after yourself as well as your child. You can get support from your child's IBD team, friends and family, other parents in a similar situation, and from Crohn's & Colitis UK.

IF YOUR CHILD HAS BEEN DIAGNOSED

Finding out your child has Crohn's or Colitis can cause a range of emotions. But you're not alone. More than 500,000 people in the UK, about 1 in 123 people, have Crohn's or Colitis. Almost 1 in 5 people with the condition are thought to be diagnosed before the age of 18. This means there are thousands of other parents in a similar situation, with similar experiences and concerns.

Will my child get better?

Crohn's and Colitis are lifelong conditions. There is no cure, but there are treatments available to help keep symptoms under control. Many of your child's symptoms should improve after they start treatment.

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

Crohn's and Colitis affect everyone differently, and symptoms can change from one day to the next. Some children will take medicines, while other children may need surgery.

Crohn's and Colitis are unpredictable. Your child will likely have periods of good health, known as remission. At these times, they may have no symptoms at all. But there will probably be times when their condition makes them feel unwell. These times are known as flare-ups, relapse or active disease. Treatment aims to control your child's symptoms and help them stay in remission.

Most children with Crohn's or Colitis continue to go to school and take part in sports and other interests. They can go on to further education, work, have a family of their own and enjoy life.

Your child's journey through life may not be what you expected, but children are very resilient. Most cope very well with their condition. Your child may have to slow down or take a break at times. But many children tell us that their condition does not stop them from 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 compete regularly. Life becomes a bit different but it's really just about remembering to do a few more things, like taking your medication."

ROSIE
LIVING WITH CROHN'S

Coming to terms with your child's diagnosis

Coming to terms with your child's diagnosis can take time for you and your family. Everyone copes differently and there is no right or wrong way of doing or feeling about things.

Many parents feel guilty or even blame themselves for their child's condition. But we do not know what causes Crohn's or Colitis, so there's nothing you could have done differently to prevent it.

"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
PARENT OF SAM, LIVING WITH CROHN'S

It's common to need time to adjust as you get used to everything. You may feel overwhelmed and out of your depth at first. Try to remember that you are not on your own. There is lots of support out there for you, including:

- Your child's IBD team
- Family and friends
- Parents of other children with Crohn's or Colitis
- Crohn's & Colitis UK

Find out more in the section Support for you.

Making time for you

It's important to look after your own emotional and physical health, even if it's hard to find the time. Try to find something that works for you. This might include taking a walk, practising mindfulness, or simply spending time with a loved one. If you do not want to leave your child with anyone else, you could invite friends to your house instead of going out.

Try to ask family and friends for help if you can. This could include support with medical appointments, or times when you need a break. There may be people who care about you and want to help, but do not know how.

"I do take it all on myself because there's so many dots to join up. The treatment, getting the drugs, making sure you've got appointments, dealing with the school. But when I can, I try and get out and have a long walk and just kind of clear my head on my own."

STUART
PARENT OF CHARLIE, LIVING WITH CROHN'S

ABOUT CROHN'S AND COLITIS

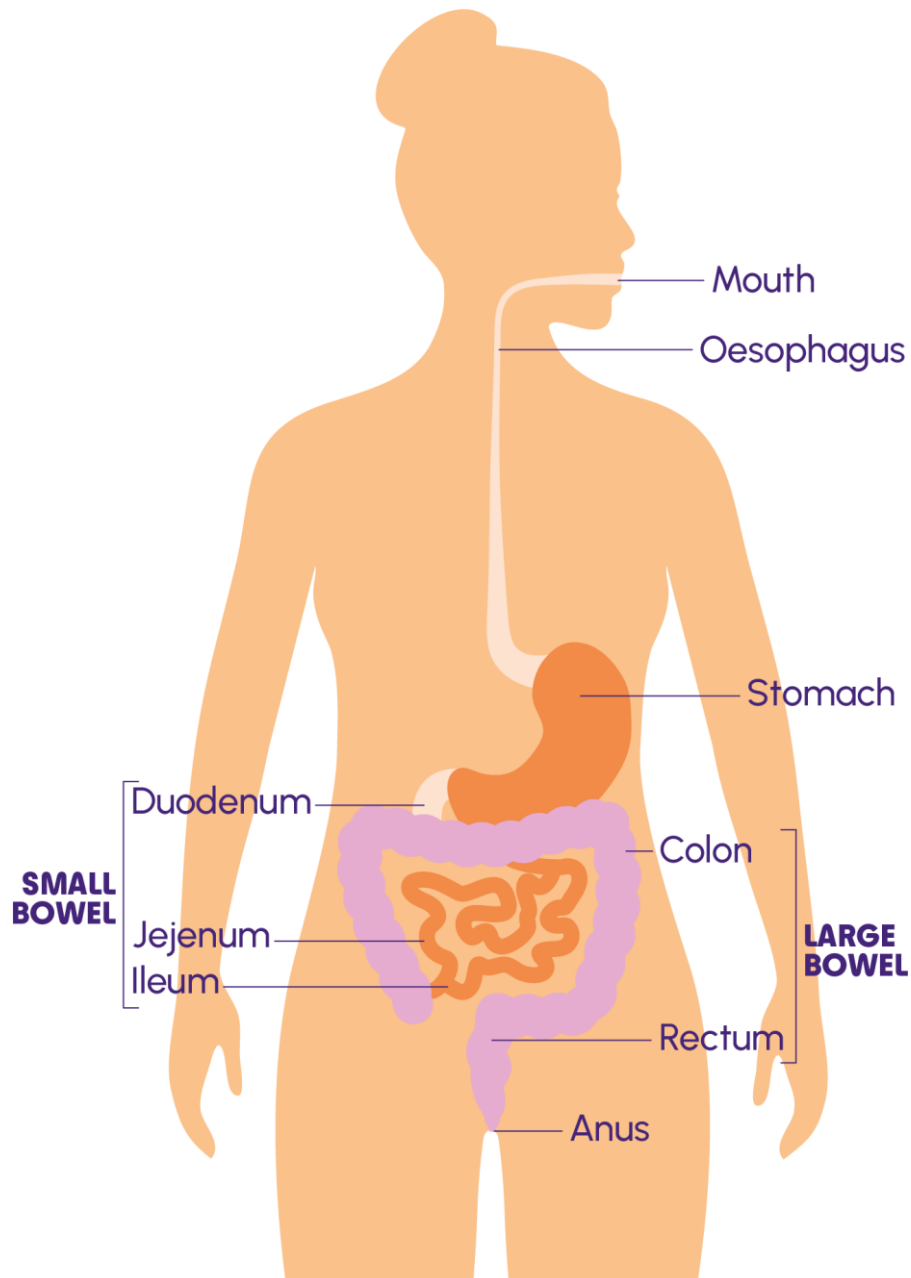
Crohn's Disease and Ulcerative Colitis are two types of Inflammatory Bowel Disease (IBD). They cause painful ulcers and inflammation in the gut.

The inflammation in Crohn's and Colitis affects how your body digests food, takes in nutrients and gets rid of poo. Crohn's and Colitis can be diagnosed at any age, but they are less common in very young children and babies. Crohn's and Colitis are lifelong conditions.

IBD is not the same as IBS, which stands for Irritable Bowel Syndrome. IBS has some similar symptoms but is a different condition and is treated differently. The NHS website has [more information on IBS](#).

The digestive system

The gut is the part of your body that takes food and nutrients in and carries poo out. The gut starts at your mouth and ends at your bottom, known as your anus.



Crohn's Disease

Crohn's can affect any part of the gut, from mouth to bottom. It's most common in the small bowel and colon. The areas of inflammation are often patchy, with sections of normal gut in between.

The walls of your bowel have layers. The inner layers take in nutrients from food, and the outer layers help move food through the gut and waste out of the body. Crohn's can affect all layers of the bowel wall.

'Crohn's Colitis' is a type of Crohn's Disease where only the colon is inflamed. This is because 'colitis' means inflammation of the colon. It does not mean your child has both Crohn's Disease and Ulcerative Colitis.

Ulcerative Colitis

Ulcerative Colitis is inflammation and ulcers in the rectum and colon, which are two parts of the large bowel. In Ulcerative Colitis, only the inner lining of the bowel wall is affected.

When we say Colitis in this information, we mean Ulcerative Colitis.

Microscopic Colitis

[Microscopic Colitis](#) is also inflammation of the colon. But unlike Ulcerative Colitis, Microscopic Colitis does not cause ulcers, and there is no blood in the poo. Only the inner lining of the bowel wall is affected. Doctors have to use a microscope to see the inflammation.

Microscopic Colitis is usually found in people over the age of 50, but it can occasionally affect children.

For more information visit our information on [Microscopic Colitis](#).

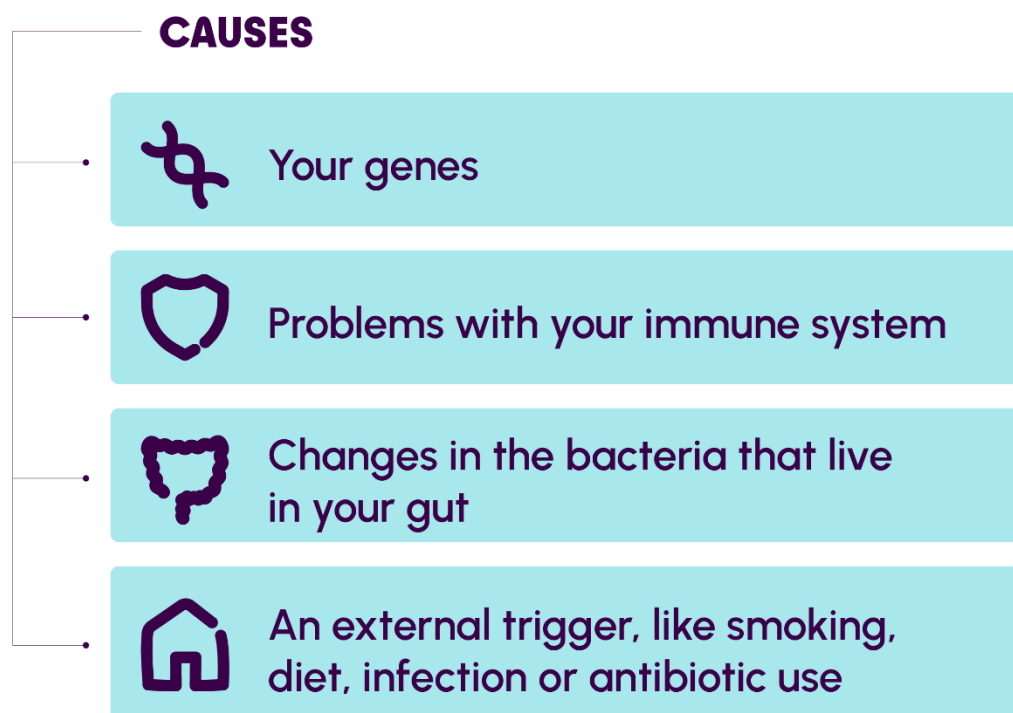
Inflammatory Bowel Disease Unclassified

Inflammatory Bowel Disease Unclassified, shortened to IBDU, is sometimes known as Indeterminate Colitis. If your child is diagnosed with IBDU, they have features of both

Crohn's and Colitis. As your child grows older their condition may change and start to look more like one condition than the other. If this happens, their diagnosis may be revisited and changed from IBDU to either Crohn's or Colitis.

The charity [CICRA](#) has more information about IBDU in children.

What causes Crohn's and Colitis?



The exact cause of Crohn's and Colitis is not known. But there are several things that may play a role, including:

- Genes. Researchers have identified more than 200 genetic variations that affect your risk of developing Crohn's or Colitis.
- A problem with the immune system. Usually, the immune system protects the body. In Crohn's and Colitis, the immune system starts attacking the body.
- Gut microbiome. The gut microbiome, sometimes called the gut microbiota or gut flora, is the natural bacteria, viruses and fungi that live in your gut.
- Environmental factors. For example, viruses, bacteria, smoking, stress, and certain medicines including antibiotics and non-steroidal anti-inflammatory medicine.

Do Crohn's and Colitis run in families?

Most people who have Crohn's or Colitis in their family will not develop either condition. But your risk is higher if a close family member is affected. It's difficult to know what the exact risk might be, but research estimates that:

- The risk of developing Crohn's or Colitis is higher if you have two or more relatives, or a sibling, with either condition.
- 5 in every 100 children might develop Crohn's or Colitis if one parent has Crohn's.
- Up to 30 in every 100 children might develop Crohn's or Colitis if both parents have Crohn's or Colitis.

A child could develop either condition, but they're more likely to develop the same condition as their family member.

It is possible for more than one child in a family to develop Crohn's or Colitis. We do not know the exact risk, and most children who have a brother or sister with Crohn's or Colitis will still not develop either condition.

Speak to your child's IBD team if you have another child with symptoms.

Symptoms

The next section looks at symptoms of Crohn's and Colitis. Everyone experiences Crohn's and Colitis differently. There's no way to know which symptoms your child might get. Or how they might be affected by these symptoms. But it can be useful to know what to look out for.

When your child is having a flare-up, they may experience:

- Tummy pain.
- Loose or watery poo, known as diarrhoea. This might be with blood, mucus or pus.
- Bowel urgency, which is a sudden need to poo.
- Difficulty having a poo, known as constipation.
- Feeling sick or being sick, known as nausea or vomiting.
- Extreme tiredness or fatigue.
- Loss of appetite and weight loss.
- Not having enough red blood cells. This is known as anaemia.
- High temperature and fever.
- Slow growth or delayed puberty, particularly with Crohn's.

"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
PARENT OF ALBERT, LIVING WITH COLITIS

Problems outside the gut

Crohn's and Colitis do not just affect the gut. Both conditions can cause problems in other parts of the body too. You might hear these called extra-intestinal manifestations, or EIMs. You may notice some of these before your child has any symptoms in their gut.

Bones and growth

Children with Crohn's or Colitis may grow more slowly, or not grow as well as other children. They may start puberty later or have weaker bones. This can be caused by lots of things, including:

- Ongoing inflammation
- Fewer nutrients taken in through their gut
- Some treatments, including long-term steroids

Your child's IBD team will consider their growth when planning treatment options with you. The aim is to manage your child's condition, while also helping them to grow and develop as normal. Talk to your child's doctor if you have any concerns about this.

Joins

Your child might have swelling, pain or stiffness in their joints, known as arthritis or arthralgia. Treatment for your child's Crohn's or Colitis can help with this. See our information on [joints](#) for more.

Mouth

Some children get mouth ulcers, sore gums, swollen lips or cracks in the corners of their mouth. This is more common in children with Crohn's and is sometimes called oral Crohn's.

Treatment for your child's Crohn's or Colitis should help with this. Their IBD team may also prescribe a medicated cream, gel or mouthwash. Take your child for regular dental check-ups, as their dentist may also be able to give advice on mouth problems.

There's some evidence that avoiding cinnamon and benzoates, which are found in some processed foods and fizzy drinks, may help. Ask your child's IBD team for a referral to a dietitian before changing your child's diet.

Eyes

A small number of children develop red, irritated eyes. Speak to your child's GP or IBD team if you're worried about their eyes. You can also go to a high street optician. This could help to avoid a more serious eye problem.

Skin

Your child may get a skin rash at the start of a flare-up. For example, they could get small painful red patches on their shins, called erythema nodosum. Skin rashes should go away as your child is treated for Crohn's or Colitis. But in some cases, treatments for Crohn's or Colitis can cause skin rashes. Speak to your child's IBD team if you notice a rash or other skin problems.

Hair

Your child might lose more hair than usual for a while. This could be due to a condition called alopecia areata or a condition called telogen effluvium. Both are associated with Crohn's and Colitis.

If your child is losing more hair than usual, speak to their IBD team to check what might be causing it. Do not stop any medicines before speaking with their IBD team.

Liver

Crohn's and Colitis can sometimes affect the liver, due to a condition called Primary Sclerosing Cholangitis. Some medicines, including azathioprine and methotrexate, can also affect the liver. Your child will have regular blood tests to check for liver problems. A change in medicine type or dose can often help any liver problems that happen.

"There were little signs 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
PARENT OF ELLIE, LIVING WITH CROHN'S

Possible complications

Some children, more commonly children with Crohn's, may also develop complications. These can include:

- Abscesses. An abscess is a pus-filled area that becomes red, swollen and painful. They are often around the bottom and can cause a fever or lead to a fistula.
- Fistulas. A fistula is a small tunnel that forms between the gut and another part of the body. For example, if your child has Crohn's around their bottom, a fistula could form between the inside of the bottom and the skin nearby.
- Skin tags. Skin tags are small growths around the bottom.

These complications can all be treated.

To find out more, see our information on [Crohn's Disease](#), [Ulcerative Colitis](#), and [fistulas](#).

Risk of cancer

If Crohn's or Colitis affects the colon, this can increase the risk of bowel cancer. This sounds scary, but the risk of bowel cancer is still very low in children. This is because the risk only starts to increase around 8-10 years after the start of Crohn's or Colitis symptoms.

It's natural to worry about your child's risk of bowel cancer later in their life. But the actual increase in the risk of developing bowel cancer if they have Crohn's or Colitis is low. Also, people who might be at higher risk can have regular bowel screening to check for early warning signs. Finding bowel cancer at an early stage gives treatment the best chance of working.

Find out more in our information on [bowel cancer risk](#) and speak to your child's IBD team if you're worried.

Very rarely, some medicines for Crohn's and Colitis can increase the risk of other cancers. This may sound worrying, and you may wonder if taking one of these medicines is right for your child. It's important to know that the risk of cancer is very small and the benefits of taking these medicines will usually outweigh the possible risk.

There are often ways to reduce the risk of side effects. For example, some medicines can increase the risk of skin cancer. Your child can lower this risk by using high protection sunscreen and protective clothing.

Always read the information leaflet that comes with your child's medicine. It will have useful information about possible side effects and ways to avoid or reduce them. Speak to your child's medical team if you are worried.

Primary Sclerosing Cholangitis, known as PSC

PSC is an inflammatory condition affecting the bile ducts. Your bile ducts are tubes that connect your gallbladder and liver to your small bowel. Bile ducts carry bile, which helps to digest food. In PSC, bile builds up in your liver, causing liver damage.

Research suggests that almost 1 in 10 people with Crohn's or Colitis develop PSC, although the real number could be even higher. If your child has PSC as well as Crohn's or Colitis, you may hear their condition called PSC-associated IBD or PSC-IBD.

PSC is more likely if your child has a lot of inflammation in their large bowel. This means it is more common in people with Ulcerative Colitis or Crohn's Colitis. PSC is also more common in males than females.

You can get support and information on PSC from the [British Liver Trust](#), [PSC Support](#), or the [Children's Liver Disease Foundation](#).

Signs of a flare-up

Flare-ups can come on suddenly, without an obvious trigger. Your child's symptoms may be different to previous flare-ups, so keep an eye out for anything unusual. Contact your child's IBD team if you're worried they may be having a flare-up. Signs of a flare-up can include:

- Tummy pain that does not go away
- Weight loss
- Diarrhoea
- Blood in their poo
- Needing to poo urgently
- Feeling sick or vomiting that does not improve after 24 to 48 hours
- Fever

Your child's IBD team should work with you to create a flare-up plan. This should include:

- What signs to look out for
- What to do if you think your child is having a flare-up
- Who to contact
- How to contact them

They can also tell you about any over-the-counter medicines that could help your child's symptoms. For example, they may be able to take paracetamol to help with gut or joint pain. But certain other painkillers, such as ibuprofen, could irritate their gut and make some of their symptoms worse. You should only give medicines to your child if your doctor has advised you to.

Some hospitals have an email service or advice line so you can speak directly with an IBD nurse. Others may have a phone number to reach the secretary or leave a message.

You might also be able to use a smartphone app to record your child's symptoms and send non-urgent questions. Ask your child's medical team if this is an option.

It's important that your child has regular check-ups with their IBD team, even if they seem well. Their IBD team will want to test their blood and poo regularly to make sure their condition is under control. How often will vary from child to child, and may change over time, so check with your child's IBD team if you're unsure.

How can we avoid flare-ups?

The best way to help prevent a flare-up is to encourage your child to follow their treatment plan and take their medicines. See the section on Supporting your child for tips on encouraging your child to take their medicines.

For some children, stress can trigger Crohn's or Colitis symptoms. If your child is going through a stressful time, such as changing schools or taking exams, they may need extra support. See the section on Supporting your child for ways to support their emotional wellbeing.

TESTS

Your child will have already had tests to diagnose Crohn's or Colitis. They will continue to have regular tests to check their condition. Your child's IBD team will say how often your child needs tests, and where these will take place. How often will depend on the treatment your child has and how well their condition is being controlled.

Tests may be different in children under the age of 5. This is because Crohn's and Colitis are uncommon in very young children and less is known about the best ways to monitor and treat this age group. If your child is under 5, speak to your IBD team about the tests that will be used to monitor their condition.

Blood tests

Your child will have regular blood tests to monitor their condition and check it is being controlled. Blood tests can be used to check for:

- Inflammation
- Signs of infection
- Low iron levels
- Whether your child is getting enough nutrients and vitamins
- The level of some medicines, to make sure your child is on the right dose

Our [tests and investigations](#) page has information on blood tests.

Poo tests

Your child's poo will also be tested to monitor their condition and check they're in remission. It can be checked for signs of bleeding, inflammation and infection in their gut.

Your child's medical team may check their poo for the amount of a protein called calprotectin. Calprotectin is released into the bowel when there is inflammation. High levels of calprotectin can be a sign that your child's condition is active and causing inflammation. Calprotectin tests are often used to monitor Crohn's and Colitis, and to check whether treatments are working.

How often your child has their poo tested will vary, so check with their IBD team if you're unsure.

Endoscopy

Endoscopy is using an endoscope to look inside your child's body. An endoscope is a long, thin tube with a camera at the end. This test will be done in the children's gastroenterology unit of a hospital.

The type of endoscopy used will depend on which part of your child's gut needs to be checked. If the tube goes down their mouth into the stomach, this is a gastroscopy. If the tube goes up their bottom into the bowel, this is a colonoscopy or sigmoidoscopy.

The doctor may also take tiny pieces of the lining of the gut, called biopsies. These biopsies can then be looked at under a microscope. They may also take photos for your child's medical records.

"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
PARENT OF ALBERT, LIVING WITH COLITIS

An endoscopy can feel uncomfortable, but it should not hurt. Children are usually offered a general anaesthetic, so that they're asleep and cannot feel anything or move around. Older children may be offered a sedative instead, to help them relax.

Preparing for an endoscopy

The hospital should give you details of when and how to prepare your child for their endoscopy. If your child is having a colonoscopy, they may need to eat a low-fibre or liquid diet for a few days before the test. They may also need to take a laxative medicine to clear their bowel. Children often find this uncomfortable, as it can cause tummy cramps. Throughout the preparation, it's important that your child drinks plenty of water.

"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
PARENT OF BEN, LIVING WITH COLITIS

Endoscopies can be upsetting for parents, particularly if your child has never had an anaesthetic before. You may find it helpful to find out exactly what will happen before your child's appointment so that you know what to expect. You can find out more about endoscopies in our information on [tests and investigations](#).

"I took so much time preparing Liv for her first cameras that I forgot to prepare myself, and when we took her to theatre for a general anaesthetic I was quite taken aback and upset."

SARAH
PARENT OF OLIVIA, LIVING WITH CROHN'S

Capsule endoscopy

Some hospitals may offer a special sort of endoscopy, called capsule endoscopy. Your child will swallow a capsule, about the size of a large jellybean, with a tiny camera inside. This takes photos as it passes through their gut, before leaving the body in their poo.

Imaging tests

Your child may have X-rays and other scans to look at their gut. These might include:

- Magnetic resonance imaging, known as MRI. This is commonly used to look at the small bowel in children. Unlike an X-ray, it does not use any radiation.
- Ultrasound. This uses sound waves to create images of the inside of the body, using a small device that is moved over your child's tummy. It can show thickening of the gut

wall and abscesses. It can also show strictures, where part of the gut becomes narrow.

- Computerised tomography, known as CT. This uses a series of X-rays to create detailed images of the gut.

For more details, see our information on [tests and investigations](#).

Managing days at the hospital

Days spent at the hospital can be stressful. There are some things you can do to make days at the hospital as stress-free as possible:

- Leave early. Allow extra time for any problems, such as heavy traffic or a late bus or train. If you're driving, give yourself time to find parking.
- Expect lots of waiting around, even for short appointments. Take some books and games or download your child's favourite film or TV show to watch.
- Take your own snacks and drinks. The hospital cafe may not be close by, or you may not want to leave your child while you go.
- Tell your child's IBD team in advance if your child is very nervous or gets upset when they see other poorly children. They may be able to find a separate room for you and your child to wait in.

TREATMENTS

Treatments for Crohn's and Colitis aim to make your child feel better, ease symptoms, and keep inflammation under control. There's no cure or single 'best' treatment for Crohn's or Colitis. Your child may have one or more of the following treatments:

- Liquid diet. This is usually only for Crohn's.
- Medicines.
- Surgery.

The treatment your child has will probably change over time and will depend on lots of things, including:

- Whether they have Crohn's or Colitis
- Whether they are having a flare-up or in remission
- How severe their condition is
- What symptoms they have
- How much of their gut is affected
- Any other health problems
- Their thoughts, and your thoughts, about treatment

Liquid diet

This involves drinking a special liquid 'food' instead of normal food. You might hear it called:

- A liquid only diet
- Enteral feeding
- Exclusive enteral nutrition (EEN)
- Nutritional therapy

Examples include Modulen IBD, PaediaSure and Ensure.

Liquid diets for Crohn's

If your child has Crohn's, this will usually be the first treatment they have when they are diagnosed. They might have a liquid diet again if they have a flare-up, or to help them grow.

Some evidence suggests that replacing some food with a liquid diet, while avoiding certain foods, could help mild Crohn's flare-ups. This treatment is not very common. Your child should only try it if suggested by a dietitian in their IBD team.

Liquid diets for Colitis

If your child has Colitis, a liquid diet will not usually be used to treat their condition. But they may sometimes be prescribed nutritional drinks, to give them extra energy for growth.

Liquid diets for IBDU

If your child has IBDU, a liquid diet might be an option, but this is not very common. Talk to your child's IBD team about whether it is an option for your child.

What does a liquid diet involve?

Your child will drink a special liquid instead of eating normal food, usually for six to eight weeks. The drinks should be spread out through the day.

We do not yet know exactly how a liquid diet works. But we know it can help with inflammation. This may encourage the gut lining to heal, while giving your child all the nutrients they need to grow properly.

Most children begin to feel better after a few days on a liquid diet. Your child may miss eating solid foods. Try to stay positive and encourage them, as this can be a very effective treatment. Your child's IBD team can support you and give practical advice on managing your child's liquid diet.

Your child will slowly start to have normal foods again over a few weeks. Their IBD team, usually a dietitian, will explain how to do this.

"My son had two courses of Modulen at the beginning of his treatment. He didn't like the taste, 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
PARENT OF THOMAS, LIVING WITH CROHN'S

Things to be aware of

You can get liquid diets from your local pharmacy with a prescription. Liquid diets come as a ready-made drink or a powder that you mix with water. Most liquid diet products are

available in different flavours, or you can add prescription flavourings to plain ones. They may be able to have other drinks too, but check with their IBD team first.

Some children get side effects like feeling or being sick, diarrhoea, bloating or wind. If your child feels hungry, contact their IBD team or dietitian.

Some families find having a liquid diet can be hard at mealtimes. Talk to your child before they start, to find out what they want to do. Some children prefer to do something else at mealtimes, rather than sit with the family.

It can also be helpful to discuss what your child wants to do during meals at school. They may be able to take their liquid diet to school, for example in a sports bottle. Check this with their IBD team or dietitian first.

"Liv did the eight-week liquid diet on diagnosis. That was quite difficult and I think none of us were quite prepared for what that meant as a family. But we got through it and then it was joyful seeing her eat her first bits of food."

SARAH
PARENT OF OLIVIA, LIVING WITH CROHN'S

If your child finds drinking hard, or really does not like the taste, they may be able to have a nasogastric feeding tube. This is a thin tube that goes through the nose into the stomach. Your child's dietitian or IBD team can help with this. Your child should still be able to go to school or college with a nasogastric tube, and take part in their usual activities. Some children feel self-conscious about it, so it could help to speak to their 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.

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

RUTH
PARENT OF EVIE, LIVING WITH CROHN'S

There's more information about a liquid diet in our information on [food](#).

Medicines

The medicines used to treat Crohn's and Colitis aim to stop inflammation, treat flare-ups, and stop future flare-ups. Your child's IBD team will explain which medicine they recommend and why. Older children may find it helpful to talk to their IBD team themselves.

All medicines can have side effects. Your child's IBD team should explain how the medicine may affect them. Make sure the IBD team know if your child gets any side effects, so they can help manage them.

There are four main types of medicine used to treat Crohn's and Colitis in children. Your child may take one or a combination of medicines at the same time. The most common medicines used to treat Crohn's and Colitis in children are listed below. There is also detailed information about each medicine on our webpage about [treatments](#).

Medicines for Crohn's and Colitis

| Type of medicine | Examples | Form |
|--|---------------------------|---|
| 5-ASAs, or aminosalicylates These medicines are mainly used for Colitis | Sulfasalazine, mesalazine | Tablets, granules, enema or suppository. Enemas and suppositories are medicines given into the bottom |
| Corticosteroids | Prednisolone, budesonide | Tablets, intravenous drip |

| | | |
|--------------------|--|-----------------------------|
| Immunosuppressants | Azathioprine, mercaptopurine, methotrexate | Tablets |
| Biologics | Adalimumab, infliximab | Injection, intravenous drip |

5-ASAs (aminosalicylates)

5-ASAs are also known as aminosalicylates. They help with inflammation in the gut so that damaged tissue can heal.

If your child has Colitis, they will probably have 5-ASAs when they are first diagnosed.^{7,10} They may take them every day for several years, even when they are well.¹⁰

If your child only has inflammation in the lower part of their colon or rectum, they may have an enema or suppository.^{7,10} An enema is a liquid medicine that goes into their bottom, while a suppository is a tablet that goes into their bottom.

Your child may not want to try an enema or suppository at first. But they work well and get the medicine straight to where it is needed to help them feel better.

Enemas and suppositories can be difficult to use at first. Get support from your child's IBD nurse when trying this type of medicine for the first time.

5-ASAs are sometimes given to children with Crohn's, but this is less common.^{6,25} They might be an option if your child has been diagnosed with IBDU.^{39,98}

Read more about [5-ASAs](#).

"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
PARENT OF EMMA, LIVING WITH IBD UNCLASSIFIED

Corticosteroids

Steroids can help to control inflammation. They can be given as a tablet, liquid, or a drip into the arm. They are not the same as anabolic steroids used by athletes to improve their performance.

Your child might have steroids:

- When they are first diagnosed
- If they are having a flare-up

If your child has Colitis, they'll usually only have steroids if 5-ASAs are not right for them or have not helped.

Steroids are very effective and can act quickly to make your child feel better. But they can cause side effects, so doctors will try to give the lowest dose that works, and for as short a time as possible. It's important to follow the instructions given by your child's IBD team. Your child should not stop taking steroids without talking to their IBD team.

Steroids can also affect a child's growth and can make teenage acne worse. Some children may become irritable, moody, or have temper tantrums. You can find out more in our information on [steroids](#).

Anyone who treats your child for another illness or injury needs to know they take steroids. Your child should carry a 'Steroid Treatment Card'. You can get one from your GP practice, hospital or pharmacy. Or your child could wear an emergency bracelet, available from pharmacies or online.

Immunosuppressants

These include [azathioprine](#), [mercaptopurine](#) and, less commonly, [methotrexate](#). These medicines help with inflammation in the gut by dampening the immune system, so that it does not attack the body's own tissues. They can take two to three months to start working, so they are not used on their own as a first treatment or to treat flare-ups. But they can help to reduce the risk of flare-ups and keep your child in remission.

If your child has Colitis, they may have immunosuppressants alongside a 5-ASA medicine. Or they may have an immunosuppressant if 5-ASAs are not helping.

We have more information on [azathioprine](#), [mercaptopurine](#) and [methotrexate](#) that you may find useful.

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

BEV
PARENT OF BEN, LIVING WITH COLITIS

Biologics

Biologics act on the immune system, but in a different way to immunosuppressants. They work by blocking certain proteins or processes that are involved in inflammation. Your child may have a [biologic medicine](#) if other medicines have not helped.

The two most common biologics are:

- [Adalimumab](#): given as an injection into the tummy or leg at home.
- [Infliximab](#): given through a drip in the arm in hospital. A drip is also known as an intravenous infusion.

Your child will need tests before taking a biologic medicine, to make sure they do not have any hidden infections.

You can find out more about the biologic your child may be offered in our [treatment](#) information.

Important points about taking medicines

- It can take a long time to find the right medicine, or combination of medicines, that works for your child. Your child may try one or more treatments that do not help,

before finding one that does. This can be frustrating but is quite common. Ask your child's IBD team how long it should take for their treatment to work, and contact them if it does not help.

- You may want to keep a diary of your child's medicines, symptoms, side effects and responses to treatments. This can help you keep track of changes over time. It will remind you of any ups and downs in your child's condition between appointments and help you and your child's IBD team to spot any patterns.
- The symptoms of Crohn's and Colitis can change as your child gets older, so their treatment may also need to change over time.
- Contact your child's IBD team if you're worried between appointments.
- If you think your child is having an allergic reaction to a medicine, speak to their GP immediately. If your child shows signs of having a life-threatening allergic reaction, call 999.
- Steroids, immunosuppressants and biologics can affect your child's immune system. This means they may not fight infections as well as other children. Speak to your child's doctor if they've been around anyone with an infection like chicken pox or measles. This is particularly important if your child has not been vaccinated.
- Your child will probably not be able to have certain vaccines while on steroids, immunosuppressants or biologics. Read more about vaccinations when your child has Crohn's or Colitis.
- Immunosuppressants and biologics can make your child more sensitive to sunlight. Make sure your child is properly protected by covering them up, keeping them in the shade and using a high protection sunscreen.
- Speak to your child's IBD team before giving them any other medicines. Other medicines might interact with their treatment for Crohn's or Colitis. This includes over-the-counter medicines that you buy yourself, and herbal or complementary therapies.
- Your child's IBD team will ask if your child is taking their medicine. They may also ask how your child is supported to take their medicine. If your child is struggling, see the section on encouraging your child to take their medicines.

Your child should only stop taking their medicines after talking with their IBD team.

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. Some research suggests that around 2 in 10 children with Crohn's, and nearly 1 in 10 children with Colitis may need surgery.

Surgery may be an option if your child:

- Is not getting better with medicines
- Has very severe inflammation
- Only has inflammation in one part of their bowel
- Has a stricture or fistula due to Crohn's

If you are thinking about surgery, the IBD team will refer your child to a surgeon. The surgeon will explain the operation and talk through any concerns. Your child may be able to have keyhole surgery known as a laparoscopy, where only small cuts are made. People usually recover faster and have less pain after keyhole surgery, but it is not always an option.

Surgery should only happen after careful discussion between you, your child and their IBD team. You can read more in our information on [surgery for Crohn's Disease](#) and [surgery for Ulcerative Colitis](#).

SUPPORTING YOUR CHILD

"George has coped really well with his 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
PARENT OF GEORGE, LIVING WITH CROHN'S

Helping your child cope with their diagnosis

It's important to take care of your child's emotional and mental health as well as their physical health. Feelings of anxiety, low mood and stress can affect many parts of their everyday life. This could include their school, social and family life, confidence, self-esteem and sleep. Poor mental wellbeing could stop them taking medicines properly, and make symptoms like pain and fatigue worse.

There are some things you can try to help your child cope with their condition.

Try to keep life as normal as possible

Having Crohn's or Colitis will mean some changes in your child's life. But wherever you can, try to live as normal a life as possible. Routines are important for children. Try to keep doing your usual family activities but be prepared to change your plans at the last minute if your child is too tired or unwell. If your child is disappointed, you can reassure them that you'll do those activities or outings when they feel better.

"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 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
PARENT OF HARRY, LIVING WITH CROHN'S

Be open and honest with them

Your child, like you, will probably need time to get used to their diagnosis. Explain what's happening in words your child understands. 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 tell them: 'The needle will feel like a sharp scratch, but it'll be over before we can count from ten to one. Then the doctors and nurses will be able to help you.'

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

ROB
PARENT OF HARRY, LIVING WITH CROHN'S

Stand up for them

Some parents have difficulty in getting healthcare professionals to take their child's symptoms seriously. In these situations, it's important to listen to what your child is saying and keep pushing for answers. You might want to read about [Stacey's experience](#) of getting her son, Louis, his diagnosis.

"If I was asked what advice I'd give to other people trying to advocate for their loved ones who are experiencing symptoms – just keep pushing. Keep pushing for answers and don't be afraid to be 'a pain'."

STACEY
PARENT OF LOUIS, LIVING WITH CROHN'S

Help them find their 'flare hobby'

It may help if your child can find a happy way to pass the time during a flare. Your child might enjoy reading, audiobooks, computer games, films, or learning a new craft or instrument. If they're old enough, you can find free lessons for most things on YouTube.

Encourage them to make the most of the times when they're feeling healthy. You could tell them about people whose Crohn's or Colitis has not stopped them from having exciting lives. Examples include magician Dynamo, racing driver Jonny Edgar, Strictly dancer Amy Dowden, and former 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. I have always been driven to win, so Crohn's wasn't going to hold me back."

AMY DOWDEN
PROFESSIONAL ON STRICTLY COME DANCING, LIVING WITH CROHN'S

Connect with other children

Children may 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 across the UK. The charity [CICRA](#) has an E-Pal scheme, which gives children a chance to chat with other children with Crohn's or Colitis.

Get them involved

There are lots of things about Crohn's or Colitis that your child cannot control. But you can give them choices about their care, when possible. This can help them feel more in control. For example, which arm they'd prefer the needle in, or what they'd like to do after taking their medicine.

Show them simple ways to manage their condition. Younger children could put on their own 'magic cream' to numb their skin before blood tests, or their own plaster afterwards. Older children could gradually have more responsibility for managing their own medicines.

Use play to ease fear and anxiety

Try taking a doll or teddy along for blood tests. It could help to pretend that the toy is a patient and use it to explain what will happen.

Children's nurses at the hospital are often used to encouraging this type of play. But appointments at the GP surgery are often shorter, and the practice nurses may have less time to prepare your child or use toys. In this case, it may help to arrive early so that you have extra time to play and prepare your child while you wait.

Help them see the funny side of things

At times, having a sense of humour could help your child feel better. It might help them realise that their symptoms are not embarrassing. Some parents tell us that it's good to laugh about things, as long as the child feels comfortable and does not think you are laughing at them.

Get professional help if you're worried

If you're worried that your child is not coping with their diagnosis, it may help them to talk to a psychologist or counsellor. Their IBD team might be able to help with this.

Your child's emotional wellbeing

Your child will experience ups and downs, just like any other child. But you might notice more worrying changes in their mood or behaviour at times. Signs they may be struggling include:

- Sadness or a low mood that does not go away
- Being irritable or grumpy all the time
- Not being interested in things they used to enjoy
- Avoiding time with friends and family
- Having trouble sleeping, or sleeping more than usual
- Behaviour changes at school or at home

Encouraging your child to talk is an important first step. They may find this difficult, so keep trying and stay positive and encouraging. Make sure they know that you want to listen and choose a time when there are few distractions. Younger children may find it easier to draw what's worrying them. Teenagers may be more likely to open up if you're side by side, for example sitting in the car or going for a walk.

Your child may find it easier to talk to another trusted adult, such as a close family member, someone in their IBD team, or their favourite teacher. Whoever your child chooses to talk to, discussing their worries can help them to see things differently and find ways to cope.

Parents and healthcare professionals have found several ways to support children's emotional wellbeing. There may be something here that could help your child:

- Write down how they feel or keep a mood diary. Older children could try the NHS recommended [Kooth](#) app, which has a space for keeping a journal. They can also get support from other young people and professionals through the app.
- Do what makes them feel relaxed, like watching a film, reading a book or playing a game.
- Younger children may find it helpful to act out their feelings with their dolls or cuddly toys. You can then help them to think of ways to make their toys feel better.

- Teenagers could try the NHS recommended [Tellmi app](#). This is a safe space to open up and get positive advice and support from other young people. All posts and replies are checked to make sure the comments are kind.
- Practise deep breathing, meditation or yoga. Apps or YouTube videos can guide them through these techniques.
- Go for a walk, take part in sports or exercises they enjoy, or try something new.
- Try painting, colouring, or another type of craft.

If you're concerned about your child's emotional wellbeing, talking to a counsellor might help them. Check if your child's IBD team has a counsellor or clinical psychologist, or ask if they can refer your child to one. Your GP practice or child's school may also have a counsellor. Your child could also speak to someone on a helpline such as [Childline](#), or [Children 1st](#) in Scotland.

[Young Minds](#) has a helpline for parents and adults worried about a child's mental health. And our information on [mental health and wellbeing](#) has more about what counselling is and how it can help.

Encouraging your child to take their medicines

It's important for your child to take their medicines as prescribed, to keep them well and prevent flare-ups. This can be difficult for children. Some parents have told us their children rebel, while other children may simply forget. Children who do not take their medicine are at a higher risk of flare-ups and severe disease. Parents can play an important part in helping their child take their medicines. Some of the following ideas may help:

- Make it part of their routine, just like brushing their teeth or having a bath.
- Try setting reminders on a phone.
- If your child's medicine tastes bad, have a drink or small treat ready to take the taste away.
- For younger children, you could use a reward chart.
- Play can often be a good way to get young children to take medicines.

- Involve older children in managing their own condition. If they're taking lots of different medicines, a medicine box with the days of the week can be a helpful way to keep track.
- Encourage older children to keep a diary of side effects, ask questions at check-ups, and take part in decisions about their treatment.
- Try to stay positive and encouraging. Remind your child that the medicines should help them to feel better, and to stay feeling better.
- Talk to your child to understand what they dislike about their medicines. They might have side effects, struggle to swallow their tablets, or simply find it a chore. Your child's IBD team are there to help. If they know what your child is struggling with, they can give you extra support.

Try to remind your child why it is important for them to take their medicine.

Resources for children and young people

There are lots of resources and services that may be helpful for children living with Crohn's or Colitis.

[The Unstoppables](#)

The children and young people in this information all have Crohn's or Colitis. They've shared their stories and advice for other young people.

[Meet our Crohn's and Colitis cats](#)

A colourful story book and animation to help explain Crohn's and Colitis to children. You can watch the animation or download the book on our website.

[All about Crohn's and Colitis](#)

This has basic information about Crohn's or Colitis for anyone who is new to the condition. The easy-to-read format makes this a useful resource for teenagers and young people.

['What are Crohn's and Colitis?' animation](#)

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

Talking Toolkit

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

'Telling my friends' animation

An animation based on research with young people with Crohn's or Colitis, funded by Crohn's & Colitis UK.

Young person films

Five young people discuss challenges such as school, university and relationships, and share their own ways of coping.

Transition: moving to adult care

A guide for older children moving to adult care, written with the help of other young people.

Concessionary Membership

16 to 18 year olds are eligible for concessionary Crohn's & Colitis UK membership. This means membership is cheaper or free, depending on your situation.

CICRA

CICRA are a charity that support children with Crohn's or Colitis to live as normal a life as possible. Their website has information and videos for children and young people.

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.

LIVING WITH CROHN'S OR COLITIS

Talking about your child's condition

Crohn's and Colitis are often described as invisible conditions. Your child might look fine on the outside, even if they have painful or distressing symptoms. This can make it hard for

other people to know how unwell they are, but it's up to you and your child how much you tell family and friends.

Negative reactions may be more likely when a person does not understand the condition. Other parents may be unsure of what your child can eat. Some might even worry that the condition could be infectious.

"I did initially get a bit cross having to explain everything to people who seemingly couldn't understand. But I didn't know anything about IBD until it impacted my family, so you need to bear that in mind when speaking to others and be patient."

STUART
PARENT OF CHARLIE, LIVING WITH CROHN'S

Being open and honest is usually the best way to tackle any confusion. It could help to talk to your child's friends, or their parents if the friends are young. Check that your child is happy with this first. 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. We've put together lots of tips to help start conversations in our [Talking Toolkit](#).

Helping your child feel confident when out

Being able to get to a toilet can be a worry for people with Crohn's or Colitis. Here are some ways to help your child feel more confident when out and about:

- Carry an emergency kit with wet wipes, disposal bags and spare clothing, just in case.
- [Become a Crohn's & Colitis UK member](#) and receive a Can't Wait Card. Your child can show this when they need to use a toilet quickly, without having to explain their condition.

- Get a RADAR key to open accessible 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](#).
- If you're travelling by car, keep a small 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 find this information at toiletmap.org.uk.
- Information in the section on Family Holidays might also be helpful.

Diet and food

Eating with Crohn's or Colitis is different for everyone. Apart from a liquid diet for Crohn's, no single diet has been proven to help in the long term. The main thing is for your child to eat a healthy, balanced diet when they can. This is essential for their continued growth and development. A [Mediterranean diet](#) is one example of a healthy diet that includes all the nutrients your child needs. They should also drink plenty of water to avoid getting dehydrated.

Some children find that certain foods trigger their symptoms or make them feel worse when they're in a flare-up. Common examples include spices, herbs, dairy products, and high-fibre foods such as vegetables, nuts and wholegrains. But everyone is different.

If you think a particular food is affecting your child, try keeping a food diary to record what they eat and any symptoms they get afterwards. It may help your child to avoid certain foods that upset their gut. If Crohn's is affecting your child's mouth, it might help to avoid cinnamon and benzoates. Cinnamon and benzoates are found in some processed foods and fizzy drinks. But you should always talk to their doctor or a dietitian before cutting out any foods, to make sure your child does not miss out on important nutrients.

Regular blood tests will show if your child is low in any vitamins or minerals. If needed, their doctor will prescribe supplements or nutritional drinks. Your child should not need to take extra vitamins or minerals, unless advised by their doctor.

Our information on [food](#) has more details on healthy eating with Crohn's or Colitis. Your child's IBD team may also be able refer you to a dietitian.

Encouraging your child to eat

Children with Crohn's or Colitis may be thin or underweight. Your child may lose interest in food if they're having a flare-up. They may be scared to eat if this might cause symptoms, or make their symptoms worse.

It can be difficult for a child with Crohn's or Colitis to eat enough to reach their ideal weight and height. Your child's IBD team may recommend nutritional drinks to top up their calories. Speak to your child's IBD team if you are worried.

Avoiding foods: avoidant restrictive food intake disorder (ARFID)

Some people with Crohn's or Colitis may start to refuse certain foods, without advice from a dietitian. Sometimes, this behaviour can become extreme and lead to an eating disorder called ARFID.

ARFID is when someone avoids certain foods, or limits how much they eat. We do not yet know how common ARFID is, but some research suggests it may affect almost 2 in every 10 people with Crohn's or Colitis. It could increase your child's chances of malnutrition, where the body does not have enough of all the nutrients it needs.

Your child might develop ARFID if they think certain foods have made their Crohn's or Colitis symptoms worse. Or if they get anxious or afraid when they eat.

Tell your child's IBD team if you notice them avoiding or refusing any foods. They may suggest a referral to a dietitian, or to Child and Adolescent Mental Health Services (CAMHS), for specialist support.

The charity Beat has [more information about ARFID](#).

"Patrick's diet is restricted due to sensory difficulties. He has ARFID, he has an aversion to anything he doesn't know. All he eats is bland food. The guilt of me feeding him pizza and sausages when I know this is not healthy, but it's all he will eat, it's not easy."

ANDREEA
PARENT OF PATRICK, LIVING WITH COLITIS, AUTISM AND ARFID

Sport and exercise

Sports and exercise are a big part of life for many children, and your child should still be encouraged when they are well. Exercise can have positive effects on mood, self-esteem, sleep quality and energy. In a study of Crohn's & Colitis UK members, 7 in 10 said that exercising made them feel better. Early research also suggests it may help to improve bone health in children with Crohn's or Colitis. You can find out more about exercising with Crohn's or Colitis in our information on [being active](#).

If you're not sure whether your child should take part in certain activities or sports, speak to their IBD team.

Managing fatigue

Fatigue is an overwhelming feeling of tiredness, low energy and exhaustion that does not go away after rest or sleep. It's very common in people with Crohn's or Colitis. Fatigue can have a big impact on your child's school, social and family life. Your child may need to take more time out, pick and choose what they do, and learn that it's OK to say no to things.

Fatigue can be difficult to manage. Some people say they find some of the following things helpful:

- Take each day as it comes. Encourage your child to do what they can in bite-size pieces.
- Make sure you include lots of rest time when planning activities or days out with family or friends.
- Let your child rest when they say they need to. Try to remember they're not being lazy and that this is part of their condition.
- Explain that it's OK to go at a slower pace than they might usually. Speak to your child about their favourite activities and prioritise doing these.
- If your child feels well enough, encourage them to go for a short walk or spend time sitting in the garden or a local park. Gentle movement and spending time in the fresh air could help to boost their energy levels.
- Try to manage how much energy they have for tasks. Think about saving up energy when you know they have something big coming up, or something they really want to do.
- Help them create a fatigue kit. This could include a favourite short walk, things to watch on TV, food to eat, and music to listen to.

It can be hard to know exactly what is causing fatigue. For example, it could be caused by inflammation, some medicines, or low levels of certain nutrients. If your child is struggling, speak to their IBD team. They may be able to suggest ways to help your child manage their fatigue or prescribe supplements if needed.

See our information and animation on [fatigue](#) for more information and support.

"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
PARENT OF EVIE, LIVING WITH CROHN'S

School

School is a key part of your child's life and it's important for them to go as much as they can. Some children do not want to tell people about their condition. But telling your child's school can help them understand your child's condition and needs.

Get in touch with the school and ask to create a plan together, to help manage your child's condition at school. You might want to ask for a meeting with you, someone from the school, and a member of your child's IBD team. This can be a quick and simple way to make sure everyone has the same information.

Try to build a good relationship with your child's form teacher and the person who arranges learning support. This person is likely to be:

- In England: the Special Educational Needs coordinator, known as the SENCO
- In Wales: the Additional Learning Needs coordinator, known as the ALNCO
- In Northern Ireland: the SENCO or Learning Support coordinator
- In Scotland: the Additional Support Needs teacher, known as the ASN teacher

This can make it much easier to raise problems and find solutions if needed.

Ask them to read the information on our website, including the information on [supporting students](#). The charity CICRA also has lots of information about schools. You may find it helpful to give copies of their [resources for schools](#) to your child's school, so that staff know how to support your child.

Make sure staff have any information they need about your child's treatment. This includes possible side effects and ways to manage them. Tell them if your child's medicine affects their immune system, so they can let you know about any illnesses in your child's class.

Using the toilet

Some schools have strict rules about using the toilet during lessons. Your child might need a 'toilet pass' so they can leave class whenever they need the toilet. Contact your child's school to arrange this as soon as possible. They may ask for a signed letter from a healthcare professional. Your child's GP or IBD team can help with this.

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

DONNA
PARENT OF CHARLIE, LIVING WITH CROHN'S

Make sure your child's teachers know that your child may sometimes need the toilet suddenly. They may have to leave the class more than once, or for a long time. They might also miss the start of lessons if they're in the toilet. Knowing this means your child's teachers will not tell your child off or ask questions that could be embarrassing.

Managing homework

Feeling unwell or tired could make it harder for your child to do their homework and hand in projects on time. Your child may find some of the following tips helpful:

- Encourage your child to make the most of times when they are feeling well and have the most energy.
- Try not to leave homework until just before the deadline. Getting ahead, when possible, means your child will have time to spare if they have a bad day.
- Your child may find it easier to listen to short films or documentaries online, rather than reading when they feel tired.
- Show your child how to plan ahead, using a calendar, diary or phone app. Break large pieces of work into smaller chunks, leaving extra time for breaks or early nights. Make sure they know their plans may need to change, and that's OK.
- Do not expect your child to study every evening. They may feel different from one day to the next. This means they may have days when they do no homework, and days when they can do extra.
- Consider inviting school friends over so that they can do homework together. Some children find this easier and more fun than studying alone.

- If it's clear your child will miss a deadline, encourage them to tell their teacher early. This will show their teacher that they are doing their best to plan ahead.
- Try not to let homework become stressful. This could make it harder to concentrate, as well as making your child's symptoms worse.

Time off school

The school also need to understand that Crohn's and Colitis are unpredictable. Your child will hopefully be well for long periods of time. But they may also have times when they are unwell. They might have to go home early or not go into school, sometimes for days or weeks at a time.

Speak to your child's teachers about their schoolwork. If your child feels well enough, the school may be able to send work by email so that they do not fall behind.

Schools' legal duties

Schools have a legal responsibility towards children with medical needs. Relevant laws include the Equality Act 2010 in England, Wales and Scotland, and the Disability Discrimination Act 1995 in Northern Ireland. Crohn's and Colitis are not disabilities. But if your child has severe Crohn's or Colitis, the law may apply to them. Schools in England must also support children with health problems under the Children and Families Act 2014.

The following organisations have more information to help you get your child the education they are entitled to:

- [Disability Rights UK](#)
- [Contact](#)
- [IPSEA](#) (in England)
- [SNAP Cymru](#) (in Wales)
- [SENAC](#) (in Northern Ireland)
- [Enquire](#) (in Scotland)

"I've got the school where I need them to be now. I typically email the form tutor and the Special Educational Needs Coordinator (SENCO) every term, reminding the school of reasonable adjustments that need to be made. I had to go super formal with them really."

STUART
PARENT OF CHARLIE, LIVING WITH CROHN'S

Extra help at school

For many children, schools can arrange enough support to meet their needs. But some children need more complex support.

England

If the school cannot meet your child's needs, you can ask your local authority to assess your child for an education, health and care plan, known as an EHC plan. This is a legal document that describes your child's educational, health and social support needs. You can read more on the [GOV.UK website](#).

Wales

You can ask your child's school to prepare an individual development plan (IDP) for your child. This is a legal document that describes your child's learning needs, the support your child should get, and who will provide it. If the school cannot provide this support, it can ask the local authority to take over your child's IDP. Read more on the [Welsh government website](#).

Northern Ireland

Your child's school may prepare an individual education plan, known as an IEP, or personal learning plan (PLP) for your child. If this does not meet your child's needs, you can ask the Education Authority to assess your child. The Education Authority may then give your child a Statement of Special Educational Needs. This is a legal document that describes your

child's needs and the support that the Education Authority must arrange. Read more at [NI Direct](#).

Scotland

You can write to the person who arranges extra support at your child's school, asking them to assess your child's needs. They may work with you and your child to create a written plan. If the school does not agree, or your child does not get enough support, contact the local authority. You can ask them to assess your child for a legally binding coordinated support plan, also known as a CSP. Read more at [Education Scotland](#).

Your child's classmates

Children all feel differently about how much they want their friends or other children at school to know about their condition. Some find it helpful if a teacher explains their condition to the class. Others may find this upsetting. Talk to your child about this and ask what they want to happen.

It's important to help prepare your child to talk about their condition and answer friends' questions in their own words. You might want to practice these conversations at home, so that your child gets used to talking about their Crohn's or Colitis.

"We talked a lot in advance of school return to help prepare my son. Most questions at his school have been about absence. 'Why are you studying at home, why can't you do PE', rather than toilet frequency."

STUART
PARENT OF CHARLIE, LIVING WITH CROHN'S

If your child is young, they could share our '[Meet our Crohn's and Colitis cats](#)' story book or animation with their class.

Exams

Stress can make some children's symptoms worse. Try to offer your child extra support during exam periods. Encourage them to find a balance between doing enough studying and staying well. Having regular breaks in revision is important. Some of the suggestions in the section on Your child's emotional wellbeing may also help them cope with stress during exam time.

Let your child's school know that their condition is unpredictable and can make exams and deadlines harder. Ask to speak with the school's exams officer so that you can explain your child's condition and the support they may need. Some schools or colleges may be able to make special arrangements, like delaying internal exams or dates for handing in work. Some children may be able to do exams in a separate room near to a toilet. Or they might be given extra time to make up for toilet breaks.

"I booked a face-to-face appointment with the exams officer at the school as GCSE mock exams were being scheduled, to ensure relevant adjustments were made. These included a seat near the exit, time out to go to the bathroom, and time added on at the end."

STUART
PARENT OF CHARLIE, LIVING WITH CROHN'S

Bullying

Children can sometimes say or do things to hurt another child, often targeting them for being 'different' in some way. Children with an illness are more likely to be bullied. It can help to be aware of the possible signs of bullying. Many are the same as those for depression, anxiety or stress. Other possible signs include:

- Not wanting to go to school, even when they seem well
- Not wanting to spend time with other children from school
- Needing to leave school early more often

- Saying they feel unwell when it's time to go to school
- Suddenly doing less well at school
- Seeming more angry than usual
- Avoiding social media.

There can be lots of other reasons for the things mentioned above. If you're worried, encourage your child to talk to you, or another trusted adult.

If they are being bullied, try to stay calm and reassuring for your child. Be clear that bullying is not OK and reassure them that you can help. Get in touch with their teacher and make sure your child knows what to do if it happens again.

The charities [Family Lives](#) and [Young Minds](#) have more information on what to do if your child is being bullied. They also have helpline services for parents.

Family holidays

Your child should still be able to go on holidays or visit family overseas. It may just take some extra thought and planning.

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

RACHEL
PARENT OF THOMAS, LIVING WITH CROHN'S

Our information on [travelling](#) cover things to think about before travelling. It includes information on travelling with a stoma and tips for staying well on holiday.

Vaccinations

It's important that your child has routine vaccinations. These include:

- Human papillomavirus, also known as HPV, vaccine: given at age 12-13. There is also a catch-up programme for people under the age of 25. The HPV vaccine helps protect against certain cancers. If your child is taking medicines that affect the immune system the vaccine may not work as well. The NHS has more on the [HPV vaccine](#).
- Three-in-one teenage booster, protecting against tetanus, diphtheria and polio: given at age 14.
- MenACWY vaccine, protecting against meningitis and septicaemia: given at age 14.

These vaccines are usually safe for children with Crohn's or Colitis, but always check with your child's IBD team first.

Flu vaccine

All children with Crohn's or Colitis should have a flu vaccine every year. Most children are offered the children's nasal spray flu vaccine at school until they are 15. If your child is on certain steroids, immunosuppressants or biologics, they cannot have the nasal spray vaccine. This is because it is a live vaccine. Your child should have a flu vaccine injection instead, as this is not a live vaccine.

Live vaccines

Your child probably cannot have live vaccines if they take steroids, immunosuppressants or biologic medicines that weaken the immune system. Live vaccines include:

- Measles, mumps, and rubella (MMR)
- Yellow fever
- Tuberculosis
- Chickenpox
- Nasal spray flu vaccines

Speak to your child's IBD team about these.

If your child stops taking a medicine that weakens their immune system, they may have to wait three to six months before they can have a live 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.

COVID-19 vaccines

COVID-19 vaccines are safe for people with Crohn's or Colitis. Your child may have a reduced response to the vaccine, or lose protection faster if they're taking medicines that weaken the immune system.

Find more information about [COVID-19 for people with Crohn's or Colitis](#).

Travel vaccines

Some travel vaccines, 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.

Speak to your child's GP or a private travel clinic at least eight weeks before you travel. You can also ask your child's GP for more general advice about travel health, such as protection against malaria.

Autism and ADHD

Supporting a child with Crohn's or Colitis can be more challenging if they are autistic or have attention deficit hyperactivity disorder (ADHD). Each child may be affected in different ways.

"My son is autistic, so this complicates things. He needs us more in terms of care and wiping his bum. Implementing a healthy diet or accepting a new medication, or anything new for that matter, is a challenge."

ANDREEA
PARENT OF PATRICK, LIVING WITH COLITIS AND
AUTISM

Things that may help

Talk to your child's professional teams

Speak to both the IBD team and the specialists who help with your child's autism or ADHD. They can help identify issues that might affect your child's care, and work with you and your child to overcome them.

For example, your child might be able to see the treatment room and equipment before their appointment, so they know what to expect. Or, if your child struggles in noisy waiting rooms, staff may show you to an empty side room or the hospital's prayer room instead.

Encourage coping strategies

Remind your child to try their usual ways of coping with the world around them. Make sure they take any helpful items they need to appointments, such as headphones, fidget toys, or an eye mask.

Get a sunflower lanyard

A sunflower lanyard shows people that your child has an invisible condition and may need extra support or understanding. You can get a sunflower lanyard and find out more about the scheme from [Hidden disabilities](#).

Learn to spot signs of discomfort

It can be difficult to know when your child is in pain or unwell if they do not use words. It may help to look for physical signs, such as bloating, wind, diarrhoea, constipation or smelly poo.

Your child's behaviour may change when they have symptoms. They may get more irritable or anxious, react more to noises or bright lights, or have trouble sleeping. Non-verbal children may scream, sigh, whine or moan. Younger children may become aggressive. Learning to spot these behaviours could help you to understand your child's symptoms.

Ask to see a psychologist

Autistic children often struggle to communicate and deal with their emotions. A psychologist could help them to open up and feel more positive. Psychological support could also help if your child has sensory issues that affect their eating or use of medicines. Your child's IBD team may be able to help with access to a psychologist.

Further information and support

The following organisations and websites may have useful information or services to help you support your child:

- Autism Central: www.autismcentral.org.uk
- National Autistic Society: www.autism.org.uk

Moving to adult services (transition)

As your child gets older, it's important that they start to take control of managing their condition. Your child's IBD team will encourage them to take more responsibility as they reach their teenage years. This is part of the 'transition' process: preparing to move your child's care from child to adult services. The formal transfer usually happens when a child is around 16, but can happen a little later. For example, your child's IBD team may decide to wait if your child is currently having a bad flare-up or is doing exams.

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

DONNA
PARENT OF ELLIE, LIVING WITH CROHN'S

Each hospital manages transition differently. Some have special clinics for 16 to 19 year olds, some offer one or two joint appointments with staff from both services, and some just send

a letter. Your child should have their own transition plan, made together with their IBD team. Ask about the process at your child's hospital.

There are lots of ways you can help your child prepare for transition. Start by letting them take more control of their medicines over time. You could sit down together before appointments and encourage them to think of their own questions to ask their IBD team. You could even let them meet their IBD team alone every now and then. This will help them to be more confident and independent by the time they meet their new IBD team in the adult clinic.

Your child might find it helpful to read our information for teenagers on [transition: moving to adult care](#). Our [appointment guide](#) can also support them in taking control of their own appointments.

SUPPORT FOR YOU

Your child's IBD team understand that their diagnosis may be challenging and distressing for the whole family. Looking after a child with Crohn's or Colitis can feel overwhelming at times. It can affect all parts of your life, from family life and relationships to work, finances and leisure time. It can also have a major impact on your emotional wellbeing. For example, some parents say they feel isolated and alone when their child is first diagnosed, or during long periods of illness. Some parents we've spoken to describe a feeling of grief for the future they had expected for their child, or guilt that they cannot make their child better. The 'up and down' nature of Crohn's and Colitis can leave them feeling anxious and on edge.

Support from your child's IBD team

IBD teams can include different types of professionals, depending on the hospital. Your child's team may include:

- Paediatric gastroenterologist. A doctor who specialises in diagnosing and treating gut problems in children.
- IBD Nurse Specialists. Nurses who specialise in supporting and caring for people with Crohn's or Colitis.
- Dietitian. A professional who specialises in diet and nutrition. They can help manage some of your child's symptoms and make sure they're getting enough nutrients.
- Psychologist. A professional who specialises in the mind, emotions and behaviour. They may be able to support you as well as your child. Read more in the section on [Counselling for you](#).

Try to build a good relationship with your child's IBD team as early as possible. You'll probably see them regularly for some years and they are an excellent source of information and advice. Your child will also need to develop their own relationships with their team over time.

You will not always have as much time as you would like to talk to your child's IBD team. Write down any questions you have in advance, so you do not forget them. It's useful to put these in a list, so you can ask them quickly and easily. Our [appointment guide](#) has other useful tips to help you get the most out of appointments.

Concerns about your child's care

If you are concerned about your child's care, you may wish to contact the following for further support:

- England: [Patient Advice and Liaison Service](#)
- Scotland: [Patient Advice and Support Service](#)
- Northern Ireland: [Patient and Client Council](#)
- Wales: [Llais](#)

If you have serious concerns about your child's diagnosis or treatment, you can ask the IBD team or GP to refer you to another specialist. Seeing another specialist can take a long time. It will depend on how long the waiting list for the hospital is.

You may find it helpful to look at the [IBD Standards](#). These set out what high-quality care looks like at every point from getting diagnosed, through to treatment and ongoing care.

Support from family and friends

It is not always easy to ask for help. Your family and friends may want to help but just do not know how. You could encourage them to visit our website to read all about Crohn's or Colitis.

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

- Take your child for blood tests, if your child is OK with this
- Pick up your child's prescription or do some errands for you
- Sit with your child in hospital while you go home to wash, sleep or spend time with your other children
- Collect your other children from school or have them for dinner or sleepovers
- Sit with your child so you can spend time with your other children

Support from other parents

Many parents say that while family and friends try to understand, it's impossible unless your own child has Crohn's or Colitis.

The charity CICRA hold family information days several times a year. These are a chance for parents and young people to meet and share experiences with others in a similar situation. Visit [CICRA](#) to find out more. Some hospitals also hold events so that people can meet other local families.

Some parents tell us they find it helpful to chat in and get support from online forums made for parents of children with IBD. But it's important to remember forums are often not moderated and should never be used for medical advice.

"I chat with friends, but unless somebody is actually going through it, I don't think they can fully understand how stressful and worrying it can be. A great support network I came across, via a magazine, is a Facebook group. These are the people that actually know what you as a parent are going through and there is so much advice, it really helps to interact with people going through similar experiences."

KELLY

PARENT OF LUCA, LIVING WITH IBD UNCLASSIFIED

Counselling for you

People have different ways of coping with the impact of Crohn's and Colitis. It may take some time to find what works for you.

If you need support for yourself, you may want to speak to someone who is professionally trained, such as a counsellor or a psychologist. Your child's IBD team may include a psychologist. If so, they may be able to support you. Your GP can also refer you to local counselling services, also known as talking therapies.

In some parts of the UK, you may be able to refer yourself for free talking therapies.

- In England, you may be able to refer yourself through the [NHS website](#). You will still need to be registered with a GP.
- In Wales, you can register for an online cognitive behavioural therapy programme, also known as CBT, through [Silver Cloud health](#).
- In Scotland, you can refer yourself for a CBT assessment at [Breathing Space](#).
- In Northern Ireland, you will need a referral from your GP.

You can also pay for private counselling. [The British Association for Counselling and Psychotherapy](#) can help you find a counsellor in your area.

[NHS Every Mind Matters](#) also has tips for looking after your mental health.

Financial help

You may find that you're spending more on utility bills, laundry, special diets, travelling to appointments, and lost days at work. 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 other children. See our information on [Claiming Disability Living Allowance](#) to check if your child could be eligible, and for information on how to apply.

If you live in England you may also be eligible for the [WaterSure](#) scheme. The WaterSure scheme is for people on benefits who need to use lots of water for medical reasons. See [Citizens Advice](#) for more information on who is eligible and how to apply.

Students at university may be able to apply for [Disabled Students' Allowance](#) (DSA). DSA can help meet the extra expenses that come with their condition, such as the cost of an ensuite room.

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

ANDREW
PARENT OF EMMA, LIVING WITH IBD UNCLASSIFIED

Our information on [finances](#) explains other financial help that could be available.

Taking time off work

It's up to you how much you tell your employer about your child's condition. Check if your workplace has any policies in place for taking time off to care for your child. They may offer more time off than the legal minimum, or let you work flexible hours.

If you are worried that your employer might not understand, ask them to read our [information](#). This may help them to understand your child's condition and the impact on your daily life better.

Unplanned time off

All employees have the right to unpaid time off work to deal with unexpected events involving their child. For example, if a child is suddenly unwell and needs a day off school. This includes permanent, temporary, full-time and part-time employees. There's no limit on how many times you can take unplanned time off, but it must be reasonable.

GOV.UK has more information on [taking time off work if your child needs you unexpectedly](#).

Planned time off

There is no legal right to time off if you knew about a situation in advance, such as taking your child to a planned hospital appointment. Some employers may let you make up the hours at another time, or you may get unpaid parental leave. If not, you will need to take annual leave.

Parental leave

You may be able to take unpaid parental leave to look after your child, for example to be with them in hospital. You may be eligible if you are an employee, have been at the company for at least a year, and have parental responsibility. There are limits on how much parental leave you can take and how much notice you must give your employer. Read more at [GOV.UK](#) and check your workplace policy on parental leave.

Flexible working

You and your employer may consider other options, such as having flexible start and finish times or working from home.

If you're unsure of your rights, the charities [Citizens Advice](#) and [Contact](#) offer free advice.

OTHER ORGANISATIONS

- Autism Central: www.autismcentral.org.uk
- Beat: www.beateatingdisorders.org.uk
- British Association for Counselling and Psychotherapy (BACP): www.bacp.co.uk
- British Liver Trust: www.britishlivertrust.org.uk
- Childline: www.childline.org.uk
- Children 1st (Scotland only): www.children1st.org.uk
- Children's Liver Disease Foundation: www.childliverdisease.org
- CICRA (a charity supporting children with Crohn's or Colitis and their families):
www.cicra.org
- Citizens Advice: www.citizensadvice.org.uk
- Colostomy UK (services include support for parents and information in the form of a story book for young children): www.colostomyuk.org
- Contact (information and advice for families with a disabled child, including education, money and family life): www.contact.org.uk
- Disability Rights UK (services include a student helpline and products to help manage bowel problems): www.disabilityrightsuk.org
- **Enquire (information about additional support for learning in Scotland):**
www.enquire.org.uk
- ERIC (information on managing bowel issues in children, including guidance for schools): www.eric.org.uk
- Family Lives (support and information for families and parents):
www.familylives.org.uk
- Great British Public Toilet Map (UK-wide database of public toilets):
www.toiletmap.org.uk
- IA (Ileostomy and Internal Pouch Association): www.iasupport.org
- IPSEA (legally based information and advice for families of children with special educational needs or disabilities): www.ipsea.org.uk
- National Autistic Society: www.autism.org.uk

- Over the Wall (a charity providing residential and online experiences for children with health challenges): www.otw.org.uk
- PINNT (Patients on Intravenous and Nasogastric Nutrition Therapy): www.pinnt.com
- PSC Support: www.pscsupport.org.uk
- Turn2Us (information on financial support you may be entitled to): www.turn2us.org.uk
- Young Minds (support for young people, parents and carers, including a parents helpline): www.youngminds.org.uk

HELP AND SUPPORT FROM CROHN'S & COLITIS UK

We're here for you. Our information covers a wide range of topics. From treatment options to symptoms, relationship concerns to employment issues, our information can help you manage your condition. We'll help you find answers, access support and take control.

All information is available on our [website](#).

Helpline service

Our helpline team provides up-to-date, evidence-based information. You can find out more on our [helpline web page](#). Our team can support you to live well with Crohn's or Colitis.

Our Helpline team can provide support by:

- Providing information about Crohn's and Colitis
- Listening and talking through your situation
- Helping you to find support from others in the Crohn's and Colitis community
- Providing details of other specialist organisations

You can call the Helpline on **0300 222 5700**. Or visit our [LiveChat service](#). You can read our information on [when the Helpline](#) is open for more details..

You can email helpline@crohnsandcolitis.org.uk at any time. The Helpline will aim to respond to your email within three working days.

Our helpline also offers a language interpretation service, which allows us to speak to callers in their preferred language.

Virtual Social Events

We offer people affected by Crohn's or Colitis the chance to join a virtual social event with others across the UK. The events will be a chance to chat, share experiences and potentially learn from others. Each event may have a specific topic but the overall discussion will be driven by what those attending wish to talk about.

Family, friends and colleagues are more than welcome to attend.

Visit our [Virtual Social Events](#) page to find out what is available.

Crohn's & Colitis UK Forum

This closed-group Facebook community is for anyone affected by Crohn's or Colitis. You can share your experiences and receive support from others. Find out more about the [Crohn's & Colitis UK Forum](#).

Help with toilet access when out

There are many benefits to becoming a member of Crohn's & Colitis UK. One of these is a free RADAR key to unlock accessible toilets. Another is a Can't Wait Card. This card shows that you have a medical condition. It will help when you are out and need urgent access to the toilet. See [our membership webpage](#) for more information. Or you can call the Membership Team on **01727 734465**.

ABOUT CROHN'S & COLITIS UK

We're Crohn's & Colitis UK and we're changing what it means to live with these lifelong gut conditions. 1 in 123 people in the UK have Crohn's Disease or Ulcerative Colitis. These are unpredictable conditions that could flare up at any time.

No one should face that alone. That's where we can help.

We provide trusted information and support cutting-edge research. We also lead bold campaigns to get more people talking about Crohn's and Colitis. We help people understand these conditions, give them the attention they deserve and bring people together to create change.

This year, 25,000 people will be told they have Crohn's or Colitis. Once diagnosed, the obstacles continue. Today, there is no cure. People simply don't understand these conditions. So, we have listened. It's time for change & we're leading the way.

Our information is available thanks to the generosity of our supporters and members. Find out how you can join the fight against Crohn's and Colitis by calling **01727 734465**. Or you can visit [our website](#).

About our information

We follow strict processes to make sure our information is based on up-to-date evidence and is easy to understand. We produce it with patients, medical advisers and other professionals. It is not intended to replace advice from your own healthcare professional.

You can find out more on [our website](#).

We hope that you've found this information helpful. Please email us at evidence@crohnsandcolitis.org.uk if:

- You have any comments or suggestions for improvements
- You would like more information about the evidence we use
- You would like details of any conflicts of interest

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

We do not endorse any products mentioned in our information.

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