



better lives for children with crohns and colitis

Very Early Onset Inflammatory Bowel Disease (VEOIBD)

Information for parents and carers



We are CICRA and we support children living with Crohn's and colitis, and their families.

We believe that all children deserve **a childhood unlimited by inflammatory bowel disease.**

CICRA was founded in 1978 to fund research into Crohn's, working towards better treatments and training of specialists. We continue to drive the development of paediatric gastroenterology in the UK.

We are working hard to find out what causes Crohn's, colitis and all forms of IBD, to help the many children and young people diagnosed each year, including a growing number under 5 years old.

We lead research into better treatments, support children and families with relevant information, work with health professionals to improve care and give children a voice to help everyone understand the impact these conditions have on childhood.

Contents

VEOIBD: What does it mean for my child?	4
What is IBD?	6
What is VEOIBD?	8
What causes VEOIBD?	11
The journey to diagnosis	12
What is life with VEOIBD like?	14
What happens after diagnosis?	16
How is VEOIBD managed?	18
How is VEOIBD treated?	20
How do I recognise the signs of a flare?	25
What about food?	26
Looking after yourself	28
Here to help	30



What does it mean for my child?

It can be overwhelming when your child is diagnosed with a long-term condition. Many parents/carers will be scared, anxious, and worried about the future.

It is important to remember that “lifelong” does not mean a shortened life. With the correct diagnosis and the support of a specialist paediatric gastroenterology team, your child should have long periods of remission with few or no symptoms. They will be able to go to school, socialise with their friends, and go on to achieve the career of their choice.

Here, we answer some of the common questions parents/carers of children with very early onset inflammatory bowel disease (VEOIBD) have. We also explain what to do when you want more information or support.



“She is literally living a completely normal life, other than the medicine that she has to take. She is absolutely smashing it.”



Rebecca, mum to Isabella who was diagnosed with VEOIBD aged one



What is IBD?

Inflammatory bowel disease (IBD) is a long-term autoimmune condition which can appear at any age. It happens when parts of the gut become inflamed (swollen).

The two main types of IBD are:

- **Crohn's disease (CD):** the inflammation can affect any part of the digestive system. It can lead to ulcers, abscesses, and strictures (narrowing) in the gut. Some children may also develop ulcers in and around the mouth. Doctors call this oral Crohn's disease.
- **Ulcerative colitis (UC):** the inflammation affects mainly the lining of the large bowel (colon) and rectum. It can cause ulcers, bleeding, diarrhoea, and tummy pain.

CD and UC are very similar and can be hard to tell apart, especially in the very young. When this happens, doctors may refer to the condition as IBD unclassified (IBDU). In some children, the condition will be classified as CD or UC later on. In others, the diagnosis will stay as IBDU, even when they are older.

Quick facts

- There is no cure for IBD, though treatments to manage the symptoms are available
- IBD is not contagious. Children cannot catch it or pass it on
- IBD should not be confused with irritable bowel syndrome (IBS), which is a common non-inflammatory disorder of the bowel



For more information, go to the CICRA website:
cicra.org/what-is-ibd/very-early-onset-ibd

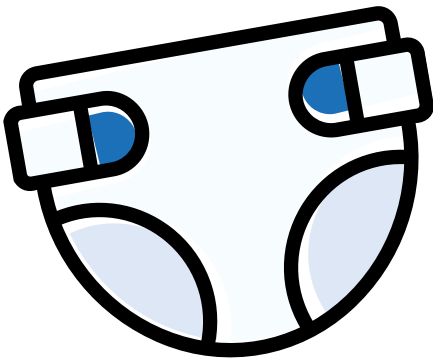
What is VEOIBD?

Doctors use the term VEOIBD to describe IBD diagnosed in a child under the age of six years. The symptoms are largely the same as those for older children who live with the condition.

Sometimes, children have symptoms that do not seem to be related to IBD at all. These can include joint pain, tender red lumps on the front of the legs below the knee, or issues with their skin or eyes.

Like all forms of IBD, VEOIBD is classed as a relapsing/remitting condition. That means the symptoms can come and go. When the child is having a relapse, sometimes called a flare, they will have symptoms. When a child is in remission, it means the condition is under control, either with or without medication. During remission, they will have no or fewer symptoms.

Successful treatment can help to prevent relapses.



Common symptoms

Each child with VEOIBD is different, but they may experience some or all of the following:

- tummy pain or discomfort;
- diarrhoea, often containing blood or mucus;
- constipation;
- being sick;
- poor appetite;
- weight loss;
- not growing or developing as expected;
- skin tags, lumps, or ulcers in the area around the anus;
- an abnormal passageway between the inside of the anus and the skin around the anus (fistula);
- fever;
- joint pain;
- extreme tiredness (fatigue).





What causes VEOIBD?

No one knows what causes VEOIBD. **What we do know is that it is nobody's fault.** Nothing you have done has caused your child to develop VEOIBD.

IBD is an autoimmune condition. It happens when the body's natural defence mechanism (immune system) reacts inappropriately, and starts to attack the gut. It can happen at any age.

Researchers do not yet know why this happens. It is likely to be a mix of things, including the make-up of the bacteria in the gut (microbiome), the environment, and genetics. However, IBD is not a genetic disease. Certain genes may make it more likely that a person will develop the condition, but it does not mean they definitely will. If your child has a family member with a form of IBD, tell your GP and hospital team.

A minority of children with symptoms of VEOIBD will have a specific genetic abnormality. This is most common in those who are younger than two years when they start experiencing symptoms. The NHS will routinely test for genetic causes. If they find one, your healthcare team will explain it to you in detail, and the treatments and specialists available to your child may change.

“IBD happens for a multitude of reasons. It is no one's fault. The younger the child is, the higher the chance that a single genetic mutation is responsible. But, overall, that chance is still very low.”



Dr Jochen Kammermeier, Consultant Gastroenterologist,
Evelina London Children's Hospital

The journey to diagnosis

Diagnosing VEOIBD can be difficult. The symptoms, such as diarrhoea and being sick, can look the same as typical childhood illnesses.

Your GP will likely want to exclude other, more common causes of your child's problems. They may, for example, suggest cutting out certain foods in case it is an allergy.

Of course, very young children cannot explain how they feel or where the pain is. Parents can look for visual clues, such as blood in the nappy. It can also be useful to keep a note of when this happens, along with a food diary. This can help to identify or rule out allergies. Remember to take any notes you make to the GP or hospital on every visit.

GPs may suggest simple tests which can offer clues as to whether or not your child has VEOIBD. These include blood tests, to look for signs of inflammation, and stool sample tests, to look for calprotectin. Calprotectin is a protein white blood cells in the gut release when there is inflammation.

If there is a suspicion of IBD, the GP should refer the child to the nearest paediatric gastroenterologist. They will have the skills and equipment to carry out the necessary tests. So that the best treatment can be given, tests are needed to confirm a diagnosis. These may include blood and poo tests, an MRI scan, ultrasound or a colonoscopy, where a flexible tube with a camera on the end is inserted via the bottom to see the inside of the bowel. Your nurse will explain more.

The important thing to remember is that you know your child best. Work with your GP to get to the bottom of what is going on. Once other possible causes have been ruled out, do not be afraid to ask for a second opinion, or for a referral to a paediatric gastroenterologist.

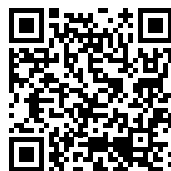


“I kept going back to the GP and felt like I was being ‘that parent’. But, as I said at the time, I would rather be neurotic than negligent.”



Ruth, mum to Aaron who was diagnosed with VEOIBD aged two

Many parents describe diagnosis as the hardest part of the journey. Once treatment is started and a specialist team is involved, families often feel they have a clearer path forward.



Find out more about tests for IBD at
[cicra.org/what-is-ibd/diagnosis](https://www.cicra.org/what-is-ibd/diagnosis)



What is life with VEOIBD like?

When in remission, there is nothing a child living with VEOIBD cannot do: it is about giving them as normal a childhood as possible. They can go to nursery or school, go on holidays, enjoy time with friends, and take part in activities. Just go at your child's own pace and be aware of relapse symptoms.

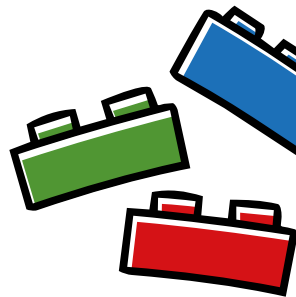
“If the child is having a flare, obviously there will be limitations to what they can do. When they are in remission, I positively encourage them to engage in everything they want to. That is really, really important.”



Dr Jochen Kammermeier, Consultant Gastroenterologist,
Evelina London Children's Hospital

When they are having a flare, the symptoms may appear suddenly, or they may build up over time. It helps to think ahead, be flexible with plans and arrangements, and watch out for signs of tiredness and discomfort.

“My biggest fear was whether her life was going to be normal, but nothing stops her. If you saw her now, you would have no idea. She is so full of life and energy.”



Rebecca, mum to Alice who was diagnosed with VEOIBD aged three

There are some considerations when starting nursery or school. Immunosuppressant medications like steroids and biologics can make children more susceptible to infections. It means they may need to take time off if a classmate has an infectious childhood illness such as chickenpox. This will very much depend on your child and the medications they are taking. Your child's healthcare team will be happy to discuss this with you.

You could consider vaccinating your child against chickenpox, if they have not already been exposed to the infection, before they start certain immunosuppressant treatments. Your medical and nursing team will be able to support you with the relevant advice.

Work with the nursery or school to give them as much information as you can about your child's condition. This will help make any necessary adjustments, and make sure they know what to expect and what to do if your child has a flare.

“IBD is part of our lives, but it is not the main thing. He is able to do everything he wants to do, and, while I wish he did not have to be, he is so resilient.”



Sarah, mum to Finn who was diagnosed with VEOIBD aged four



For more information on starting nursery or school, go to
cicra.org/how-we-can-help/schools-and-colleges

What happens after diagnosis?

Your child will be looked after by a specialist paediatric gastroenterology team, with regular clinic appointments designed to monitor their progress.



NICE quality standards are clear statements that describe what good, safe, and effective healthcare should look like. Written by the National Institute for Health and Care Excellence (NICE), NHS services use them to help make sure patients receive high-quality care wherever they are treated.

Overview of NICE Quality Standards for IBD

Statement 1

People with suspected IBD have a specialist assessment within four weeks of referral.

Statement 2

Services provide age-appropriate support from a multidisciplinary team for people with IBD, and their family members or carers.

Statement 3

People having surgery for IBD have it undertaken by a colorectal surgeon who is a core member of the inflammatory bowel disease multidisciplinary team.

Statement 4

People receiving drug treatment for IBD are monitored for adverse effects (side effects).

Most children living with VEOIBD will experience periods of remission and occasional relapses. When they are in remission, they will have no or fewer symptoms. When they are having a relapse, they will experience symptoms.

It is important to know that it may take time to find the treatment that works best for your child. Your healthcare team will be with you every step of the way.

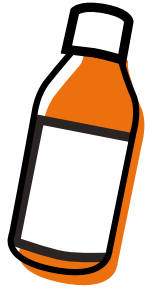
They will monitor several things to see how well treatment is working. They include your child's symptoms, growth and weight, as well as blood and stool tests, such as faecal calprotectin. Sometimes, they will suggest scans or endoscopy (a camera on a tube) to get a better idea of your child's health. Looking at all these together helps the team understand how well the inflammation is controlled and whether any treatment changes are needed.



How is VEOIBD managed?

There is no cure for IBD, but treatments to manage the symptoms are available.

Your child can still go on to live a full and happy life and to achieve their dreams.



Children with any form of IBD should have access to a specialist paediatric gastroenterology healthcare team. This should include a consultant, a specialist nurse, and a dietitian. At times, your child might need to see other healthcare professionals, such as a psychologist.

Your main point of contact will be your specialist nurse. Usually, they will only ever be an email or a telephone call away. They will also be able to refer your child to other healthcare professionals if and when they need them.

“Have a normal life and do all the things you want to do with your children. When they are relapsing, then it is over to us, the healthcare professionals, to tailor their care.”



Nancy Mew, Advanced Nurse Practitioner in Paediatric Gastroenterology, Oxford Children's Hospital





How is VEOIBD treated?

Treatments are tailored to the individual child, and you will work closely with the healthcare team to find the right one.

“Every child is different, every family is different, and treatments will be individually tailored and assessed for each child.”



Nancy Mew, Advanced Nurse Practitioner in Paediatric Gastroenterology, Oxford Children's Hospital

Treatment tends to focus on two areas: inducing remission and keeping children as well as possible between relapses



1) Inducing remission (getting flares under control)

In most cases of CD, the healthcare team will first recommend a specially formulated liquid diet. It comes as a drink, though many children do not like the taste. In this case, the liquid is delivered through a naso-gastric tube (feeding tube). This tends to last for a few weeks, during which the child does not have any other food. Once the flare is under control, parents/carers can reintroduce solids gradually, starting with bland, easy-to-absorb foods. This treatment does not have any side effects. If they feel well enough, the child can still go to nursery/school and take part in their normal activities. Sometimes, the healthcare team will recommend steroids to get a flare under control. It is different for everyone, but it can take anything from a few days to 12 weeks for a child to respond to treatment.

“Sometimes, parents can be worried about feeding tubes. But feeding and treatment is often a time of pressure for families. The feeding tube can ease some of that, and make sure they get the nutrition and the treatment they need. It is uncomfortable but it is not painful.”



Gemma Lee, Paediatric Gastroenterology Clinical Nurse Specialist, Evelina London Children's Hospital

In children with UC, doctors may recommend a type of drug called mesalazine if the condition is mild. When the condition is moderate or severe, they will usually suggest the child take steroids as well as mesalazine. The type of steroids will depend on the child. In moderate cases, the healthcare team will often prescribe oral steroids the child can take at home. When the condition is more severe, the child may need to have steroids through a drip in hospital.

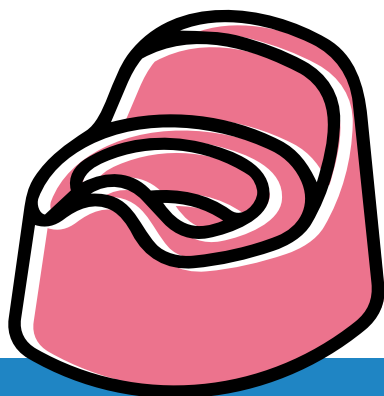
2) Keeping children as well as possible between relapses

Your child's healthcare team may recommend long-term medicines called immunosuppressants. There are different types of immunosuppressants. They include immunomodulators, such as thiopurines, and biologics, such as anti-TNF alphas.

"I was terrified of Alice going on immunosuppressants. I thought she would end up picking up every virus at pre-school and be off ill all the time, but she hasn't at all. In fact, she hasn't caught anything in all the months she's now been on them, and, even better, they got her calprotectin levels down from in the thousands to a normal level within one month. I know this isn't the case for every child, and I am so grateful that this has been our experience. I wish the version of me who couldn't sleep at night worrying about immunosuppressants could see Alice now."



Rebecca, mum to Alice who was diagnosed with VEOIBD aged three



Find out more about the different treatments available at
cicra.org/what-is-ibd/treatments

Immunosuppressants work by reducing the overactive immune responses that cause inflammation. The different types target different parts or types of immune response. There is no way to know which of these will work for your child ahead of time. Doctors may need to try several before they find the right one. This can be frustrating, but researchers are looking into this. In the future, we hope healthcare teams will be able to personalise the medication to the child.



“The best medicine for your child is very individual. Often, the best medicine will be the one they are happy to take.”



Gemma Lee, Paediatric Gastroenterology Clinical Nurse Specialist, Evelina London Children's Hospital

Very occasionally, a child with VEOIBD may need surgery. This will be a joint decision between you and the healthcare team.

Remember to write down any questions you have and do not be afraid to ask the team to explain each answer to you.



Find out more about surgery at
[cicra.org/what-is-ibd/surgery](https://www.cicra.org/what-is-ibd/surgery)



How do I recognise the signs of a flare?

Sometimes, it can be hard to spot some of the signs of a flare in children under the age of six years. Babies in particular cannot tell their parents they are in pain.

“It is about spotting patterns and trends in your child. If you notice things are going on for a few days, it may be a good idea to contact your IBD nurse.”



Nancy Mew, Advanced Nurse Practitioner in Paediatric Gastroenterology, Oxford Children's Hospital

It is different for every child, but changes in behaviour, mood, energy, appetite or toilet habits can all be possible signs of a flare. Other clues may include being quiet or withdrawn, or not wanting to engage with others. They may lose their appetite, or only want to eat bland, simple foods. But remember, not everything will be IBD. All children will have ups and downs.

“Your child can still just have an upset tummy or vomit, without it being related to their IBD. If your child is in distress or possibly has pain, have open and honest conversations with your healthcare team to explore the options.”



Dr Jochen Kammermeier,
Consultant Gastroenterologist,
Evelina London Children's Hospital



What about food?

There is no special diet for children living with VEOIBD. Healthcare professionals simply recommend a healthy, well-balanced diet. Importantly, there is no need to stop breastfeeding babies with VEOIBD.

“You should certainly not think that the mother’s milk is in any way responsible – if anything, breastfeeding can only be a positive.”



Dr Jochen Kammermeier, Consultant Gastroenterologist,
Evelina London Children’s Hospital

The most important thing to remember is not to avoid any specific food unless your healthcare team has recommended it. You should never cut out particular foods, whether that be gluten or dairy, for example, without first speaking to the healthcare team. Children need the vitamins and minerals from food to grow and develop.

“If you are going to change your child’s diet, make sure you are doing so with the guidance of a dietitian.”



Gemma Lee, Paediatric Gastroenterology Clinical Nurse
Specialist, Evelina London Children’s Hospital

If you suspect your child is having a relapse, speak to their healthcare team. They can tell you if you need to change anything the child is eating. You can also speak to your dietitian. A food supplement, in the form of a milkshake, can sometimes be useful.

During a flare, your child may just pick at food, or refuse to sit at the table with the family. Children with CD often say that they feel full up all the time. This is all normal. Try not to place too much attention on it, and avoid making meal times a battle. Things will improve when the child is in remission and feels well. Gentle encouragement and small portions, while asking them to sit at the table and eat only what they can, may help to prevent problems like 'food aversion' later on.



“With a few specific exceptions which your IBD team can advise you on, a healthy, varied diet is best. Nothing your child eats is going to cure a flare, or make it worse.”



Nancy Mew, Advanced Nurse Practitioner in Paediatric Gastroenterology, Oxford Children's Hospital



Find out more about diet and nutrition at
cicra.org/what-is-ibd/diet-and-nutrition



Looking after yourself

Caring for a child with VEOIBD is hard. But if you do not look after yourself, you will not be able to look after your child.

“I think I withdrew a bit too much at the start, which is the worst thing you can do. Be honest with other people when it is hard. Make yourself go and see your friends, or to do something nice on your own. Look after yourself.”



Sarah, mum to Finn who was diagnosed with VEOIBD aged four

It is perfectly normal to feel scared, angry, or overwhelmed. Many parents/carers even feel guilty. They think they may have caused the illness. This could not be further from the truth. We do not know what causes IBD, but we do know it is nothing that you have done.

“IBD is no one’s fault. The family really needs to understand this so they can get over the guilt, move on, and say ‘let’s tackle this’.”



Gemma Lee, Paediatric Gastroenterology Clinical Nurse Specialist, Evelina London Children’s Hospital

Remember to share the load, and make the most of your support network. Think about the family and friends you have around you. Who could you ask for help, whether that is with practical things like looking after your child’s siblings while you are at the hospital, or emotional support, like someone to listen when it all gets too much?

“I was really struggling so I called CICRA who put me in touch with another mum in the same situation as myself. For the first time since Alice’s diagnosis, a weight lifted and I no longer felt alone.”



Rebecca, mum to Alice who was diagnosed with VEOIBD aged three



Here to help

Some people find it helps to talk to people who are going through similar experiences. CICRA can help by putting you in touch with other parents/carers to talk to. We also run regular Family Days across the UK, giving parents and young people the opportunity to share experiences and connect with each other.

You can also contact us with any queries, questions, or concerns you may have, on:

support@bicra.org

**Pat Shaw House, 13-19
Ventnor Road, Sutton,
Surrey, SM2 6AQ**

020 8949 6209

f @CICRAcharity



www.cicra.org

**“My advice would be to
not Google too much.
Go to a CICRA Family
Day to meet other families
whose children are doing
well because it is so nice
to see people just living
normal lives.”**



Rebecca, mum to Isabella, who was
diagnosed with VEOIBD aged one

**We believe that all children deserve
a childhood unlimited by inflammatory
bowel disease**



Get more support and resources at
www.cicra.org

Pat Shaw House
13-19 Ventnor Road
Sutton, SM2 6AQ

020 8949 6209
support@cicra.org
www.cicra.org

f **@** **@CICRAcharity**



CICRA is the operating name of Crohns In Childhood Research Association, a registered charity in England and Wales (number 278212) and Scotland (SC040700)