



Supporting a young child with IBD

A guide for anyone caring for a child under six with inflammatory bowel disease (IBD).

For childminders, nursery and pre-school staff, carers and relatives.

This factsheet has been created for early years settings caring for a child with very early onset inflammatory bowel disease (VEOIBD). It provides simple information to help you understand the condition and develop an individual care plan.

Key points

- Every child with VEOIBD is different.
- A child may look well, even when experiencing symptoms.
- Changes from the child's normal pattern are important.
- Follow the child's individual care plan and notify parents/carers of concerns promptly.



What is VEOIBD?

VEOIBD describes inflammatory bowel disease (IBD) in a child under the age of six years.

IBD is a long-term health condition of the digestive system. It happens when parts of the gut become inflamed (swollen), leading to sores or ulcers. There is no cure for IBD, though treatments to prevent or manage the symptoms are available.

There are two main types of IBD:

- Crohn's disease (CD): the inflammation can affect any part of the digestive tract
- Ulcerative colitis (UC): the inflammation mainly affects the large intestine (colon)

Some children with CD may develop inflammation and ulcers in and around the mouth. Known as oral Crohn's disease, it can be painful and affect eating and drinking.

The signs and symptoms of Crohn's and UC can be very similar, especially in young children. Some children may be diagnosed with IBD unclassified (IBDU). This means doctors cannot tell which type of IBD they have.

Noticing changes and keeping parents/carers informed

Young children, especially babies, cannot always tell us when they are uncomfortable or in pain. Getting to know what is usual for each child can help you notice small changes in how they are feeling. They may seem more tired, unsettled or quieter than usual, be less interested in playing, or want to eat less. You may also notice changes when they use the toilet or have their nappy changed, such as more frequent or looser poos. These changes can sometimes be signs of a flare, when their IBD becomes more active.

Not every change will be due to IBD, all children have ups and downs. **You do not need to decide whether a child is having a flare, but please share any concerns with their parents or carers, including what you have noticed and when it started.** Keeping parents informed helps them spot patterns across home and childcare and seek advice from their child's IBD team if needed.

If a child seems unwell or you are concerned, contact their parents promptly and follow their agreed care plan.



VEOIBD | Quick facts

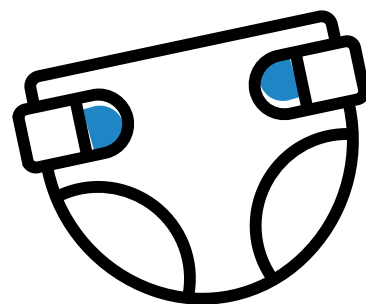
- 1 VEOIBD is an **autoimmune condition**. It happens when the body's natural defence mechanism (immune system) reacts inappropriately, and starts to attack the gut.
- 2 VEOIBD is **not contagious**, meaning it cannot spread from one child to another.
- 3 Some children with VEOIBD take medications that calm or suppress the immune system. It means they may be more likely to contract infections. **Common illnesses, such as chickenpox, can be much more serious for them.** Parents/carers may ask to be informed promptly if some infections are circulating within the setting.
- 4 VEOIBD **can make potty training more difficult.** During a flare, children may have sudden or urgent diarrhoea, accidents, or discomfort when using the toilet. Babies may need frequent nappy changes.
- 5 Some children with VEOIBD **may have small amounts of blood in their stool** or nappy. Any blood should be reported to parents/carers, even if it is consistent with the child's usual symptoms.
- 6 Some children with VEOIBD **may use a feeding tube** when they are having a relapse. This is to make sure they get the nutrition and the treatment they need to bring the flare under control.
- 7 **Children's needs, medications, and symptoms can change over time.** Regular care plan reviews can help early years childcare settings ensure they have the most useful and up-to-date information.
- 8 **Fatigue is a common symptom.** Children with VEOIBD may become tired more quickly than their peers and may need additional rest or support during the day.
- 9 Children experiencing diarrhoea, vomiting, or poor appetite may be at **increased risk of dehydration** and should be encouraged to drink regularly in accordance with their care plan.
- 10 Very young children may be unable to communicate pain verbally. **Changes in behaviour** such as becoming withdrawn, unusually upset, clingy, tired, or reluctant to participate in activities may be signs that they are unwell



"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



My child's VEOIBD

Symptoms, triggers, and what to do

Every child with VEOIBD is different. This section allows parents/carers to share important, individualised information with the childcare setting.

We recommend reviewing this information regularly, and keeping the most up-to-date version of this document with the child's care plan. Teams can also place a copy on a notice board that is clearly visible to all staff, but not visitors.

Photo here

Child's name:

Parent/ carer name(s) and contact details:

Date completed:

Medical information

Diagnosis:

Managing hospital:

Medication:

Please notify me at the **end of the day** if my child experiences any of the following (eg, diarrhoea, tummy pain, or fatigue):

Please notify me **straightaway** if any of these things happen during the day:

Please notify me **straightaway** if any of these infections are known to be circulating the setting:

My child has these **dietary requirements**:

Additional notes:

For childcare setting use – Date of next review:

For more information on VEOIBD,
visit the CICRA website at www.cicra.org