

**“If I had my  
arm in a plaster,  
people would  
understand.”**

**how to help children  
with crohns or colitis  
at primary school**

**cicra** 

better lives for children with crohns and colitis

CICRA's vision is for a childhood unlimited by inflammatory bowel disease. Through sensitivity, flexibility and support, schools can make a huge contribution to this goal.

This guide is not intended to replace specific advice from a doctor or any other professional. CICRA does not endorse or recommend any products mentioned.

images by Vicki Sharp Photography

## what is IBD?

Inflammatory bowel disease (IBD) is a **life-long condition**, which is **very unpredictable** and can have frequent flares and relapses. There are **two main types of IBD, Crohn's disease and Ulcerative colitis**. IBD is increasing in incidence and is affecting children at a much younger age. IBD is **not contagious**. It should also not be confused with irritable bowel syndrome (IBS), a less serious condition.

When IBD is active, pupils will need **regular and prolonged access to toilets**, as a common, embarrassing and distressing symptom is frequent diarrhoea. However, the impact of the disease is wider and many children suffer especially with **fatigue and pain, fever, nausea, loss of appetite, loss of concentration and lack of energy**. Some children also live with pain and inflammation of the skin, joints and eyes. Some children may suffer from peri-anal Crohn's disease, this can cause pain and/or discharge, and **may require surgery** to the area around the bottom.

Many children with IBD are **small for their age**, making them appear younger than their classmates which can **make them a target for bullies**. Combined with the strain of living with their condition, this can make them become withdrawn, anxious and depressed. Relapses can be particularly **difficult to deal with emotionally**.

Children with IBD **require treatment with medicines**. **Steroids** are a common treatment and have distressing side effects, which affect a child's appearance (e.g. **weight gain, puffy face and acne**), mood and behaviour. Others suppress the immune system, leaving children more vulnerable to normal infectious diseases like chicken pox. Some children will also have a **nutritional feed via a nasogastric tube**.

Children with IBD will need to visit hospital for **regular routine appointments and for invasive investigations**, including endoscopy. Some children will require surgery to remove diseased sections of the bowel. Some may need a stoma as part of a colostomy or ileostomy procedure.

## primary schools

It can be easier to support a child with IBD in primary school than in secondary school, as children typically have one or two class teachers and teaching assistants who know them well and can liaise with parents about a child's health, treatment and specific needs.

## what are schools' responsibilities?

Staff in schools are generally keen to support children and young people with health needs and can refer to guidance from government education departments to help them. The guidance sets out a school's responsibility to have a written policy on supporting children's medical needs. This should include:

- what the school will do when told a pupil has a medical condition (this applies before a diagnosis is confirmed)
- how the school handles prescription medicines
- staff training
- details of individual health plans
- what happens in an emergency
- arrangements for medical support on school trips and during sport

If a child's needs are complex, the school may decide to provide an individual healthcare plan (IHP). IHPs are considered appropriate for long-term, complex, recurring and fluctuating conditions.

As IBD meets these criteria, children with IBD may need an IHP. However, every child with IBD is different and needs should be assessed individually. These plans should be reviewed annually and typically cover:

- the medical condition, its signs and symptoms and treatments
- precisely what help the child needs to manage their condition
- who needs to be aware of the child's condition
- specific support needed around the child's educational, emotional and social needs

Healthcare plans for individual children should be drawn up in consultation with the child's parents or guardians.



## how can the school help?

Understanding and support from a child's school and teachers can make a tremendous difference to the child's attitude to learning and attendance, allowing them to get the most from their education. Regular communication between teachers and parents is important. In addition to discussing the condition with the pupil and their family (particularly if there are concerns about attendance or concentration), it can be helpful for schools to have contact with the medical team, with the family's consent.



## access to toilets

Children with IBD need access to clean toilets, with lockable doors that provide as much privacy as possible. Children need free access to toilets throughout the day.

It would be very supportive for schools to discuss with parents and children with IBD what reasonable adjustments can be made in order to have a toilet plan that addresses these concerns. For example, some schools have agreed that the child use a disabled, visitor or staff toilet instead. Children with IBD should also have somewhere to wash if necessary and store clean clothes.

Most children with IBD carry a Can't Wait card, which they can use to show staff if they need to leave the room urgently to use the toilet. CICRA can provide Can't Wait cards for free, which include a photo of the child. Please email [support@cicra.org](mailto:support@cicra.org)

It is important that children with IBD are allowed to leave class without explanation, as they can have an accident or being questioned can cause embarrassment, particularly if a child does not want classmates to be aware of their condition.



**“My greatest problem is being able to get to a toilet in time.”**



**“Trained office staff and teachers helped my son through a period of steroids and naso/gastric tube feeding when he was in reception.”**

## medications and side effects

During the school day the school has a duty to take sole care of a child and their medical needs and to administer medication.

Some children will need to have a liquid nutritional feed, which needs to be kept refrigerated. Children should be able to have their feed with their peers at lunchtime.

Children on certain medications will need to use sunscreen and wear hats out of doors and this should be accommodated within uniform policy.

Children on steroids can experience changes in mood and behaviour.

If children are on immune-suppressing medication or steroids and have significant contact (play or direct contact for at least 15 minutes) with chicken pox or measles (without being immune) they may need protective antibody treatment so should be removed immediately from the class if a case is suspected in another child. Parents should also be informed promptly of outbreaks of infectious diseases (such as winter flu and stomach bugs) so that children can be kept at home.

Children may also need access to water and snacks during the day and have the option to take a rest break. They may also need flexibility and extended deadlines on homework depending on their state of health and levels of fatigue.

New treatments are emerging for IBD so schools should ask parents about their child's treatment and any side effects that may need to be taken into consideration.

## inclusion

If they feel well enough, most children want to be included in all the normal activities of school including sport, trips and special occasions. Sometimes a bit of forward planning is needed; for example, considering dietary needs if an activity includes food or cooking.

Schools cannot exclude children from school trips on the basis of medical conditions, nor can they require parents to accompany them. Children should be allowed to participate fully in out-of-school activities and their specific needs should be considered as part of the normal risk assessment for school trips. For example, allocate them an aisle seat so they can get to the toilet quickly and easily.

## SATS and tests

Children often find tests stressful and stress can cause IBD to be more active. Flexibility around the start time of tests and free access to the toilets is important for children with IBD.

Visit our website [cicra.org](http://cicra.org) for information on exams and tests.

**“My disease sort of isolates me, but if I feel well I do want to join in.”**





**“When I am in hospital I like to hear from friends and teachers – it makes it easier to go back.”**

## attendance

Children and parents should not be penalised if their absence from school is related to their health condition. Parents should follow the school's attendance procedures for notifying absence.

If the absence is longer than 15 days, the local authority is under a duty to ensure the child receives as normal an education as possible. The local authority should provide a written statement on how education is to be provided. A full-time education should be provided unless the child's health needs mean a part-time education is more appropriate.

When absences are under 15 days, many children still want to keep up with key subjects, particularly if they are well and at home during an outbreak of infectious disease. Providing children with some work to do at home helps them keep up with the rest of the class.

Children with IBD often find their symptoms are at their worst in the morning, so flexibility should be allowed if children are frequently late for school. Most families would like children to start the school day as soon as they are able and not wait until break times to join their class.

## friendships and bullying

Some children don't want other pupils to know about their condition so withdraw from social activity. The symptoms of IBD mean they may not feel confident in joining their friends for normal social activities like birthday parties, sleepovers or swimming. This can make them feel socially isolated, as can hospital stays.

Some of the physical side effects of treatments (like the puffy face associated with steroids) and the general taboo about poo can make children targets for teasing and bullying. Oral Crohn's, while not affecting all children with Crohn's, can be disfiguring as it affects the mouth and lips, and lead to bullying because of appearance.

Others whose disease is 'invisible' with no outward physical symptoms can be perceived to have special privileges (for example, coming in late or leaving class without explanation), and this can cause resentment among peers. Teachers should support children with the emotional difficulties of IBD.

## transfer to secondary school

Transferring to secondary school can be both an exciting and daunting prospect for any child. Encourage children to ask about support for health conditions when they visit secondary schools.

### Sources:

- 1 Supporting pupils at school with medical conditions, statutory guidance for governing bodies of maintained schools and proprietors of academies in England, Department of Education 2015.
- 2 CICRA factsheet: Supporting children with medical needs in schools
- 3 Royal Free Hospital Children's School, letter to examiners
- 4 CICRA research
  - surveys with children with IBD and their parents
  - two focus groups with young people with IBD
  - consultation with teachers who are parents of a child with IBD
  - consultation with secondary school teachers

**“If I had my arm in a plaster people could understand.”**



if you have questions about IBD or its impact on young people then contact us

**support@cicra.org**

**0208 949 6209**

we have illustrated pages for younger children and information for young people and adults on our website

**cicra.org**

CICRA is a charity that receives no government grants and relies entirely on donations and fundraising to deliver our services and fund research. Your support can make the difference for a child living with Crohn's, colitis or IBD.



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better lives for children with crohns and colitis

Crohn's in Childhood Research Association

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