



## INFORMATION SHEET

# CHILDREN AND YOUNG PEOPLE WITH IBD: A GUIDE FOR SCHOOLS

A summary of key points and tips on how school staff can help pupils with IBD is given at the end of this leaflet.

Please circulate this to everyone involved with the wellbeing of pupils at your school.

### WHO IS THIS INFORMATION SHEET FOR?

You'll find this guide useful if you work in a school or another education environment with children or young people.

Please show this to everyone involved with the wellbeing of pupils where you work.

If you're the parent or carer of a child or young person with IBD, then you could use this guide as a way to engage with the school about your child's needs.



The school were very supportive and Alex did well in his GCSEs and went on to Sixth Form. He is now on an apprenticeship and doing incredibly well.

**Christine**, mum to **Alex**, age 17, diagnosed with Ulcerative Colitis in 2007

### INTRODUCTION

In the UK, at least one person in 210 has Crohn's Disease or Ulcerative Colitis, known as Inflammatory Bowel Disease or IBD. These are lifelong conditions that can start in childhood, and studies suggest around a quarter of people with IBD are aged under 16 when they are diagnosed. If you work in a primary or junior school then you may only occasionally meet a child with IBD, but if you work in a secondary school then it's much more likely that you'll work with at least one pupil with the condition.

With the help of parents, children and young people with IBD, we have produced this guide to provide you with some general information about Inflammatory Bowel Disease (IBD), its symptoms, treatments and their side effects.

At times, living with IBD can make school difficult for children and young people, but every child with IBD is different and most can continue to go to school, take part in sports and other interests and do as well as their peers. Most then go on to further education, training or employment.

Knowing about the physical and emotional impact the condition can have on young people can help you and the school provide the best possible support, which will allow them to thrive and achieve the best from their time at school both academically and socially.

**All four nations of the UK have some legal framework or statutory guidance that places a responsibility on schools to care for children who may have additional support needs. There are more details and further information about this on page 13 of this guide.**

## GETTING STARTED

To support a child with Inflammatory Bowel Disease (IBD) properly, your school should refer to the policies relating to looking after children with medical conditions in your country. In the UK these vary depending on the particular nation. We have provided a brief overview of the policies relating to the different nations at the end of this information sheet (see **Appendix**).

We have suggested practical ways to meet the guidance and laws throughout the leaflet. Some general things to think about are:

- Establishing good relationships with the child, their parent or carer and their Paediatric Nurse Specialist or IBD team.
- Having plans and policies in place to meet the needs of a child with a medical condition such as Inflammatory Bowel Disease.
- Extra training for staff.

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## WHAT IS INFLAMMATORY BOWEL DISEASE?

Awareness of the symptoms and possible impact of having Inflammatory Bowel Disease is a key starting point. This can help you to implement policies encouraging the child or young person with IBD to enjoy all aspects of school life.

IBD is an invisible condition – while your pupil might look ‘okay’ on the outside, they may be in a daily battle with serious medical problems.

IBD is also complex, fluctuating and affects people in different ways. So it is important to discuss each pupil’s particular needs with them and their parents, and possibly also with the health professionals involved in their care.

Inflammatory Bowel Disease is the name given to a group of conditions, of which Crohn’s Disease and Ulcerative Colitis (UC) are the two main forms. It is not always possible to distinguish between the two, and a child may have a diagnosis of IBDU (IBD Unclassified) or Indeterminate Colitis.

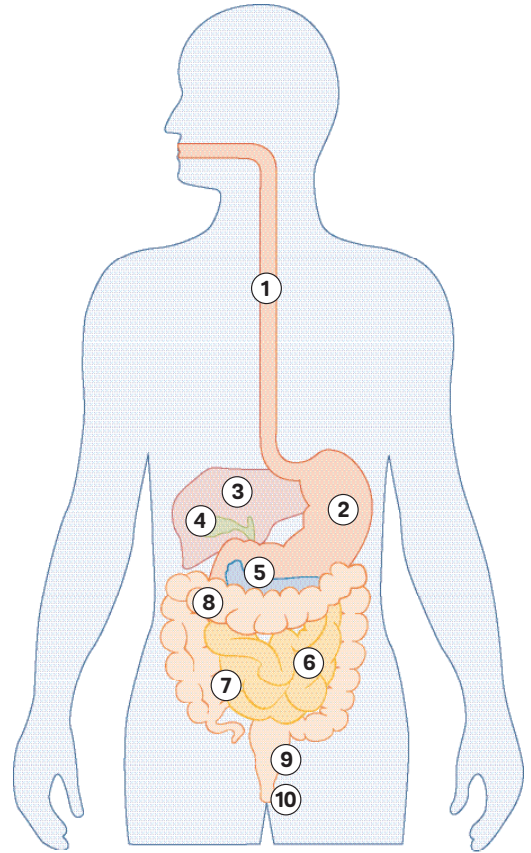
IBD is not the same as IBS (Irritable Bowel Syndrome). IBS is a different condition and is treated differently, although some symptoms can be similar to IBD.

Crohn’s Disease and Ulcerative Colitis both cause inflammation of the digestive system. Inflammation is the body’s reaction to injury or irritation and can cause redness, swelling and pain. In Crohn’s Disease, this inflammation can occur anywhere from mouth to anus – but is most common in the small intestine and colon.

Ulcerative Colitis involves only the colon and rectum (together called the large bowel). In this disease, the inner lining of the large bowel becomes inflamed and tiny ulcers develop on its surface.

## THE DIGESTIVE SYSTEM – AND THE AREAS IBD CAN AFFECT

- 1 OESOPHAGUS
- 2 STOMACH
- 3 LIVER
- 4 GALL BLADDER
- 5 PANCREAS
- 6 SMALL INTESTINE
- 7 ILEUM
- 8 LARGE INTESTINE (COLON)
- 9 RECTUM
- 10 ANUS



### WHAT THEY ARE NOT...

- They are not infectious or contagious.
- They are not the same as Irritable Bowel Syndrome (IBS).
- They are not cancer.
- They are not curable, at least not at present.

### WHAT ARE THE MAIN SYMPTOMS?

Inflammatory Bowel Disease is a chronic condition, which means it is ongoing and life-long. Although children and young people with IBD may have long periods of good health (remission), there are likely to be times when symptoms are more active (relapses or flare-ups).



Remember that IBD can be quite unpredictable - which might mean feeling great one day, and utterly drained and exhausted the next. A child with IBD may need time off school to go to the hospital for planned appointments, or sometimes may have to stay in hospital.

A 'flare-up' of their condition can significantly disrupt family life, social activities and school attendance. Even when they are not having a flare-up, a child or young person with IBD can still be dealing with ongoing symptoms, such as increased bowel frequency and extreme fatigue.

Appearances can be deceptive – IBD is an invisible condition - a child or young person may not look that unwell even on a day they are feeling awful.

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When Emma had a period of terrible pain they let her use the lift and leave school early so she wasn't jostled by the other kids. 99

Helen, mum to Emma, age 19, diagnosed with Indeterminate Colitis in 2005

Symptoms of IBD include:

- pain in the stomach
- diarrhoea (sometimes mixed with blood and mucus)
- an urgent need to go to the toilet
- increased bowel frequency
- loss of appetite, weight loss and slowed growth in height (particularly in Crohn's Disease)
- nausea
- tiredness and fatigue
- feeling generally unwell with raised temperature and fever
- anaemia (a reduced number of red blood cells).

Children with Crohn's Disease may also have a number of symptoms that cause difficulties sitting down for long periods of time, including:

- Abscesses – collections of pus that can become swollen and painful. They are often found in the area around the anus and can cause a fever or lead to a fistula.
- Fistulas – these are narrow tunnels or passageways between the gut and another organ. They appear as small openings in the skin that leak pus or sometimes faecal matter. They can irritate the skin and are often sore and painful.

Some children with IBD develop associated conditions in other parts of the body. The most common ones are arthritis (inflammation of the joints), mouth ulcers and thickening of the lips, skin rashes and sore, red eyes. IBD can also occasionally affect the liver.



Extreme tiredness or pain can slow a pupil down. An understanding attitude towards lateness can help avoid making them feel uncomfortable.

DELAYS IN PHYSICAL DEVELOPMENT

Some children and young people with Inflammatory Bowel Disease may be smaller and therefore appear younger than their peers. Although four out of five children will reach their full adult height, eventually. Puberty can be delayed, so some teenagers may be behind their peers in sexual development.

TREATMENT FOR IBD

It's important to know a bit about what treatment the child or young person is having to manage their Inflammatory Bowel Disease, as this can have an impact on their life at school.

Currently, IBD cannot be cured, but a lot can be done to minimise its effects and help children live a normal life.

IBD affects everyone differently, but the aim of treatment is to make children feel better, and then to keep their symptoms under control. There are several kinds of treatment for each condition, that may be used one after another, or in combination at the same time.

There may be times when a child or young person experiencing a severe flare-up of IBD needs treatment in hospital, sometimes for several weeks.

### Liquid diet

This usually involves taking a liquid diet (also known as nutritional therapy or enteral feeding), instead of food, for a number of weeks. If a child has difficulty drinking enough of the liquid, they may find the diet easier to take through a nasogastric feeding tube (a fine tube passed through the nose down into the stomach). Once in place, a nasogastric tube should not stop them going to school, college or taking part in all their usual activities, although some children may feel self-conscious about the tube. The majority of children respond very well to this nutritional treatment. They may then go on to long term medication to help keep their condition under control.

Sometimes the high concentration of nutrients in the liquid diet can cause nausea, headaches, and a feeling of light-headedness.

Unlike Crohn's, Ulcerative Colitis cannot be treated with a liquid diet, although nutritional drinks are occasionally recommended to provide extra energy (calories) for growth.



**If the child you're supporting is on a liquid diet, they may need access to a fridge in which to store the drinks. They may also feel embarrassed or anxious about their nasogastric tube or having a different diet to their friends. See the section on Psychological effects for ways to provide support.**

### Medication

The medications used to treat IBD are designed to stop inflammation and reduce the chance of a relapse or flare-up. If a child or young person is taking drugs for their IBD, they may experience some unwanted side effects. But the child or young person's IBD team will be monitoring their health very closely and they may have regular blood tests and check-ups. The drugs may be taken as tablets, injections or by an intravenous infusion (through a drip in the arm) in hospital. If a pupil is on such treatment, they are likely to need time off school every 4-8 weeks to receive these infusions.

Pupils with IBD may need to take their medication at certain times of day, for example, before meals. You should have policies in place covering pupils who need to take medication in school. We have provided information about the legislation covering your country at the end of this leaflet (see **Appendix**). After discussion with parents, children may be able to take responsibility for managing their own medicines and procedures.

### Side effects

All drugs can cause side effects.

In particular corticosteroids (usually shortened to just steroids, but quite different from the anabolic steroids sometimes used by athletes ) can particularly affect people of school age. Side effects include

- rapid weight gain
- having a temporarily chubbier face (sometimes called “moon face”)
- increased appetite
- worsening acne
- irritability – some children revert to earlier behaviours such as temper tantrums while on steroids
- trouble sleeping
- sometimes mild memory problems and problems with concentration.

### Taking their medication

**It is important that children and young people do not stop taking their medication unless their IBD team has advised it.** In particular steroid treatment should be reduced gradually, rather than stopped abruptly, to give the body time to adjust.

If a child is on steroids, anyone treating them for another illness or in an emergency, for example following an accident, will need to know about their steroid treatment. They should carry a ‘Steroid Card’ (available from pharmacists) or wear an emergency bracelet, such as those obtainable from MedicAlert.

### Risk of infection

Some of the medication a child may be taking for IBD, such as steroids or drugs that suppress the immune system, can make them more prone to infections. In such situations, some infectious diseases, such as chickenpox, can be very serious. Even something as simple as a stomach bug might be more problematic for someone with IBD, if they can’t keep their medication down. Children with IBD, and their parents, will need to be warned if someone in their class or year has an infection.

Also, because they are more open to infection, children with IBD, should not receive certain live vaccines. These include the MMR (measles, mumps, and rubella), yellow fever and BCG (tuberculosis) vaccines.

### Surgery

Sometimes children with Inflammatory Bowel Disease need surgery. Once done, it usually greatly improves the child’s general well-being. There are different reasons for surgery depending on what type of IBD they have and how it is affecting them. Some children with severe IBD may need an operation that involves an opening called a stoma being made in their abdomen so that the child’s digestive waste products (stool or faeces that may be liquid) can drain into a bag rather than through the anus.

This may be temporary or permanent but many children with IBD and a stoma are able to continue their lives as normal, and can play sports, including swimming, and go on school trips. Work with the child, their parents and their IBD team or stoma team at the hospital, if they have one, to get advice on managing the stoma at school

Our information sheets: **Surgery for Ulcerative Colitis** and **Surgery for Crohn’s Disease** contain more advice on taking part in activities after an operation.

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I remember I used to get whispered about a lot when I was on steroids because of my weight. It would have been nice for my teacher to warn my class – I think they were just shocked. ”

Scarlett, age 17, diagnosed with Ulcerative Colitis in 2008

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When Alex was missing school, his clinical psychologist was invaluable in helping him and liaising with his teachers. ”

Christine, mum to Alex, age 17 diagnosed with Ulcerative Colitis in 2007

## PSYCHOLOGICAL EFFECTS

**All children with Inflammatory Bowel Disease are different, but some of the things they may be coping with are:**

### Feeling embarrassed and worried about their condition

For example, they may be dreading having to rush to the toilet, having ‘an accident’, creating noises or smells and, as a result, being ridiculed or bullied. Some may not even want to tell their closest friends about their IBD, or they might try and limit what they’re eating, or avoid going to the toilet.

### Issues with body image

It may be that they are distressed about being smaller, thinner and less developed than their classmates, especially if their puberty is delayed. Or, if they are taking a high dose of steroids for their treatment, they may be worried about putting on weight and becoming fatter, round-faced and spotty.

On the other hand, children and young people with IBD may not look sick, so those around them might not always believe the difficult symptoms or feelings they’re experiencing.

### Feeling socially isolated and different from their peers

This might be because they cannot eat the same foods as them, or if they miss a lot of school, or can’t join in sports and other activities. Other children might not understand their fellow pupil’s illness or why they look different. Sometimes this can lead to difficulties with friendships and in some cases bullying, which can make them withdraw from others.

### Depression and anxiety

In general, these problems are more common in people with IBD than in the ‘healthy’ population. Trying to cope with fatigue and disturbed sleep may also impact on mood and quality of life.

### Teenagers

Being a teenager can be challenging for anyone and teenagers with IBD are more likely to be depressed and anxious, and have social problems, than their peers. This may be particularly the case if they are having a disease ‘flare-up’ or are on steroid treatment. It is also likely that they will be moving from paediatric to adult care at some point during this time (you may hear this called transition), which can be an added source of stress and uncertainty. They may try and cope by distracting themselves from the difficult issues they are dealing with.

For more information see our booklet: **Transition: Moving to adult care.**

## WHAT HELPS?

### Managing stress

Some children may find that stress makes their Inflammatory Bowel Disease worse. This might mean that the stress of exams triggers a relapse of their IBD. They may need extra support at this time to ensure that they do not overdo their exam preparation.

### Learning ways to look after themselves

Encouraging children and young people to use positive coping skills can help. This can involve working with them to think about their strengths and focusing on what they can do, rather than what they can’t. An example of a positive coping skill might be helping them find enjoyable activities that fit in with their condition.



Talking to young people about the importance of taking care of themselves in other ways may also be beneficial. Examples of this may be getting enough sleep, rest and time to relax, as well as time to study.

### Getting social support

Meeting with other young people who have IBD can help with accepting their condition and feeling 'normal'. See **Help and Support from Crohn's and Colitis UK** for further details.

### Educating their peers about IBD

If the child and their parents are happy, then teaching their peers about IBD could help with developing friendships and understanding. You might do this by providing information about IBD to a small group or the whole class during a lesson. A health professional such as an IBD nurse may be able to help with this. General information about IBD is also available on the Crohn's and Colitis UK website. This could help other pupils understand more about the symptoms and may also make the pupil with IBD more confident about talking about their condition.

### Respect and boundaries

Some children and young people with IBD do not want other people to know that they have an illness, and prefer to keep things private. Most also want to be treated in the same way as any other pupil and to have expectations of them that are the similar to their peers.

### Extra support

It is helpful if the child or young person with IBD feels they have someone to go to at school if they have any worries or concerns. Some children may also benefit from further support, such as from a school counsellor, their IBD nurse or a clinical psychologist in their IBD team.

Our leaflet **Counselling for IBD** gives further details on how to find a counsellor.



### Feeling unwell at school

A child or young person with IBD may often feel tired or have a stomach ache. Pain and exhaustion affect concentration and there may be days when they feel so unwell that they need to go home. On other days, they might be able to carry on after a brief rest or a prescribed painkiller. If possible, try and allow the pupil to decide whether to go or stay. Sometimes this can be hard to judge, so get advice from their parents if you are not sure.

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## KEY PEOPLE

### School staff

It is important that key people in the school are aware of Inflammatory Bowel Disease and the individual needs of the child you're supporting. This may vary from school to school but could involve their class teacher, form tutor or Head of Year, as well as staff in the medical office and school nurse, if there is one.

### Parents, carers and family

Having a child with IBD can have an impact on parents and the wider family. If their child has just been diagnosed, it can take time for them to adjust to the fact that their child has a lifelong condition.



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The Reception ladies were very supportive and looked after Charlie whenever he reported not feeling well. They rang me straight away and we built up a really good trusting relationship. 99

Donna, mum to Charlie, age 16, diagnosed with Crohn's Disease in 2014

Dealing with diagnosis, difficult symptoms, flare-ups, treatment and the unpredictable nature of IBD, can take its toll on the whole family, including brothers and sisters. But having family support is very important for children and young people with IBD.

So, as well as working closely with the family to plan how best to support their child at school, it can also be important for the school to be supportive of the family. There may be brothers and sisters at school who might be struggling to deal with all the attention their sibling is getting, who would be reassured by support from staff.

For more information see our booklet: **IBD in Children: A Parent's Guide.**

#### The IBD team

As part of their care, the child or young person should have an IBD team. This will include a number of different health professionals supporting them. Their key contacts for advice or support in relation to their IBD may be their IBD specialist nurse, gastroenterologist or GP.

If they do have an IBD specialist nurse, s/he may be willing to come into the school and discuss ways to help support young people with IBD. It may also be possible to have their contact details in case you need any further advice or guidance.

Some children and young people may have access to a psychologist, within their IBD team, who may also be able to liaise with you and other school staff.

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### SCHOOL LIFE

**IBD shouldn't stop a child from being involved in all aspects of life at school. But there are some things to consider to make sure they have the same opportunities as their classmates.**

#### Going to the toilet

The need to go to the toilet can be frequent and so sudden and urgent that an accident can easily happen if there is any delay in getting there. Using communal toilet areas can be very embarrassing for children and young people with IBD as they may be worried about creating noises or smells. Using communal toilets may also be a problem if the child has a stoma (see **Surgery**).

These tips may help:

- Let the child or young person sit close to the door and be allowed to leave and return to the room discreetly, without seeking permission.
- Help your pupil come up with discrete ways to leave the classroom if they need to. Perhaps they could use a secret signal when they need to go to the toilet, show a '**Can't wait card**' such as that supplied by Crohn's and Colitis UK, or have a permanent lesson pass allowing absences from the classroom?
- Make sure that the child or young person isn't penalised for being late to school or lessons, as this may be because they have needed to go to the toilet.
- Allow them to use staff toilets or disabled toilets, if possible - being given a key if necessary (in accordance with the school's safeguarding policy).
- Provide them with a locker or cupboard to keep a toilet kit with wipes and a change of clothes, for example.

### **Eating and drinking while at school**

A child or young person with IBD may have difficulty in eating a normal sized meal – maybe they feel full quickly, have pain or need to go to the toilet during their meal. If they're on steroid medication, they may have an increased appetite and be eating more than usual.

Some children or young people may be following a particular eating plan advised by their doctor or dietician, for example, eating small amounts regularly, eating a low fibre diet or eating plenty of protein and energy rich foods to maintain or put on weight. Their diet may also be supplemented by liquid meals. They may need to avoid certain foods and to drink extra water. All this may mean pupils with IBD will need longer or extra meal breaks and may be eating different meals from their classmates.

Even for those not on an exclusive liquid diet, mealtimes can still be stressful and difficult if eating causes symptoms such as cramping pain, vomiting and diarrhoea.

### **PE and sport**

On good days, a child or young person with IBD may feel able to participate fully in sport and just because someone has IBD does not mean they cannot do any exercise.

It is important to bear in mind that strenuous physical exercise can trigger an urgent need to go to the toilet or cause joint pains. Even mild activity may be too much at times when a child or young person is feeling exhausted, suffering severe stomach pain, or is recovering from surgery. Bending and stretching may bring on pain or make pain worse. Team games can be particularly problematic. Some children or young people may try to push themselves so as not to let anyone down. Others may be fearful of being teased about their lack of stamina or their need for extra rests.

It is probably best to let the pupil judge what they can manage on a day-to-day basis but, as far as possible, to treat them the same as other pupils.

### **Going to appointments and missing school**

Most children with IBD will need to have regular appointments at the hospital for check-ups or treatments. Sometimes these appointments may be during the middle of a lesson. It can help if they can slip out discreetly. Equally, some children and young people may need to be prompted that they need to leave.

Although most young people with IBD can attend school most of the time, there may be times when they do have to miss school for longer periods if, for example, they are seriously unwell with a flare-up, or need hospital treatment.

It is important that they still receive a suitable education. In some cases, this may mean home education or a hospital school.

The Health Conditions in Schools Alliance produce a handy guide to help schools identify the steps they should take to ensure children with medical needs receive the support that they need in all education settings. See their website: [medicalconditionsatschool.org.uk](http://medicalconditionsatschool.org.uk)

If a pupil is recuperating at home they may be able to cope with at least some school work. At other times (such as when in hospital), they may not be able to manage as much, but they will benefit from contact and reassurance about catching up. It helps to have a process in place to make sure that the pupil can catch up once they are feeling better, for example, it may be possible to provide notes on missed lessons. Encouraging classmates to stay in touch by phone or email, or by sending cards or even visiting, can help reduce any sense of isolation.

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I was diagnosed at the age of thirteen and, from year nine, I had health agreements put into place to help support my symptoms, workload and exams.

”

Jake, age 22, diagnosed with Crohn's Disease in 2007

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Sometimes there were toilets on the coach, but the driver wouldn't let the kids use them! So I asked Emma's teachers to speak to the driver before they set off.

”

Helen, mum to Emma, age 19, diagnosed with Indeterminate Colitis in 2005

Sometimes, children with IBD may want to avoid school even when they are actually physically fine, for example, because they feel uncomfortable about symptoms, or because they are feeling worried and stressed. Some research has found that children with IBD who don't talk about their problems are more likely to be absent from school. So getting support for this early on is very important.

### Homework

On days when the disease is causing particular trouble, a child or young person may be too tired to do their homework after school. An extended deadline could be helpful. Studying for exams may also be very difficult and the pupil may need emotional support and extra guidance on how to prioritise their workload (see **Psychological effects**).

### Exams

The fact that exams take place at fixed times can put pressure on children and young people with a fluctuating and unpredictable illness. They may also have particular problems with morning exams if their bowels are most active then. They should have quick and easy access to the toilet during exams. This might be, for example, sitting close to the door nearest to the toilets and arranging in advance who will escort them to the toilet if they need to go urgently. Some pupils may also need extra time or stop the clock breaks if they have to take extra toilet breaks or if they have fatigue and need to rest.

For pupils taking public examinations, awarding bodies may make special arrangements. Schools need to submit any request for such an arrangement as early as possible. Schools and colleges may be able to postpone internal exams or dates for handing in assignments, and special considerations and arrangements can sometimes be made for national qualifications such as GCSEs, A-Levels, Nationals and Highers. Their specialist IBD nurse or GP should be able to provide a pupil with a letter outlining how their condition impacts on their school work and ability to take exams. This would be considered a reasonable adjustment under the Equality Act and Disability Discrimination Act. See **Appendix** for further details.

### After-school activities

Sometimes children and young people with IBD may find joining after school activities difficult. Encouragement and consideration will help them get more involved in school life. For example, lifts home with a school-friend could make a real difference for a pupil who finds using buses difficult.

### School trips

Trips may be very stressful for anyone with IBD if there are no toilet facilities on the train or coach, or elsewhere during the trip. Some venues can also be difficult for someone with IBD. It helps to plan in advance, for example, find out about toilets and whether they could have an aisle seat in a cinema, theatre or lecture hall.

IBD can be very unpredictable, so it may be helpful if the pupil decides whether or not to join a trip on, or close to, the day itself. If you feel unsure about whether a child should be going on a trip, work with them and their parents to come up with a plan about how to manage if they did become ill whilst away. It helps if any medication policies the school has also cover school trips.

Automatic exclusion from all trips is inappropriate and hurtful and could be challenged under disability discrimination legislation.





## CHILDREN AND YOUNG PEOPLE WITH IBD KEY POINTS – AND HOW SCHOOL STAFF CAN HELP

### What is Inflammatory Bowel Disease (IBD)?

The two most common forms of Inflammatory Bowel Disease (IBD) are Ulcerative Colitis and Crohn's Disease. IBD is an invisible condition – while your pupil might look 'okay' on the outside, they may be in a daily battle with a serious medical problems.

These are life-long, chronic conditions, which can cause severe stomach pain, an urgent need to use the toilet, diarrhoea (sometimes with bleeding), extreme tiredness, nausea and loss of appetite. IBD can also delay growth and cause weight loss. Some children and young people with IBD also have joint pains, eye problems, mouth ulcers, rashes and anaemia. IBD symptoms fluctuate and periods of remission can be followed by acute flare-ups.

Medical treatment for IBD often includes drugs which can have side effects such as weight gain, a moon-face, spottiness and mood swings. People on IBD treatment are often more prone to infections. Some children are treated by being put on exclusive liquid diets, and may have a feeding tube. IBD can be very embarrassing for a child or young person and have both a physical and psychological impact.

### ACTIONS THAT CAN HELP:

- Let the child/young person leave and return to the classroom discreetly and without having to get permission whenever they need the toilet. If other toilets are locked or some distance away, let them use a staff toilet.
- Appreciate that they may arrive late at school or for lessons because of an urgent need to use a toilet or because tiredness or joint pains have slowed them down.
- Be aware that a child/young person with IBD may need to take medication during school hours and/or need extra meal breaks.
- Respect their need for privacy. They should decide how much teachers and other pupils are told about their condition.
- Try to be alert to their psychological needs and relationships with other children.
- Let them judge for themselves if they wish to join in sport/PE or after-school activities - but don't stop them trying whatever they want to try.
- When a school trip is coming up, talk to the pupil about their needs and try and arrange to meet these, e.g. with an aisle seat at the theatre or cinema and using a coach with a toilet.
- If a child/young person with IBD is unwell at school, consider giving them time to rest rather than sending them home. They may be able to return to lessons later in the day.
- If a pupil with IBD is ill at home or in hospital, encourage the class to stay in touch by phone or email or by sending cards.
- Help a pupil who is at home to keep up with others in their class and with schoolwork if they feel up to it. Keep in contact on a regular basis and, for example, send notes on lessons and work assignments by email.

## SCHOOLS LEGAL RESPONSIBILITY AND STATUTORY GUIDANCE

### General

**The Equality Act 2010**, in England, Scotland and Wales and the **Disability Discrimination Act (1995)** in Northern Ireland – require schools to make reasonable adjustments to make sure children and young people with a disability are not at a disadvantage to their peers. A person may be considered disabled if they have a physical impairment that has a substantial and long term adverse effect on their ability to carry out normal day to day activities. The Acts cover people with ‘hidden impairments’ such as incontinence which might hinder a person from continuing with their life as they usually would.

### England

**Supporting Pupils at School with Medical Conditions** is statutory guidance issued under **The Children and Families Act 2014** that outlines how pupils at school with medical conditions should be properly supported so that they have full access to education, including school trips and physical education. Schools are required to train staff so they are able to fulfil the obligations of the Act.

This includes each school having a medical conditions policy (required by law) and each child with a medical condition having an Individual Health Care Plan (IHP), that covers their needs at school including any medication management.

For more information, see the gov.uk website: [gov.uk/government/publications/supporting-pupils-at-school-with-medical-conditions-3](https://www.gov.uk/government/publications/supporting-pupils-at-school-with-medical-conditions-3)

Download sample policies and plans from the Health Conditions in Schools Alliance: [medicalconditionsatschool.org.uk](https://www.medicalconditionsatschool.org.uk)

#### **Special Educational Needs and Disability Code of Practice (2015)**

Children with IBD may also be classified as having special educational needs, as a child with a disability that prevents them from making use of educational facilities provided for other pupils is considered to have a special education need. A child with IBD may need special provisions to be made that might include involving a Special Educational Needs Co-ordinator (SENCO) particularly during periods of active disease.

See the gov.uk website: [gov.uk/government/publications/send-code-of-practice-0-to-25](https://www.gov.uk/government/publications/send-code-of-practice-0-to-25)

### Scotland

There are a number of policies and key pieces of legislation which relate to the rights of children with medical conditions in schools. Some are listed here.

**Getting it Right for Every Child** is a national approach in Scotland to improving outcomes and supporting the wellbeing of children and young people. It incorporates legislation from the **Children and Young People (Scotland) Act 2014**.

Some key points:

- A Child’s Plan – will be available for children who need extra support
- All children and young people from birth to 18, or beyond if still in school, and their parents, will have access to a Named Person to help them get the support they need (such as a health visitor, head teacher or guidance teacher).

See the Scottish Government website:

[gov.scot/Topics/People/Young-People/gettingitright](https://www.gov.scot/Topics/People/Young-People/gettingitright)

**Education (Additional Support for Learning) (Scotland) Act 2004 and 2009**

All children with additional support needs should be engaged in personal learning planning. In addition they may need an individualised education programme (IEP) or a co-ordinated support plan, if they have more complex needs, involving other agencies such as health services. Parents and young people should be included in this decision making.

For more information, see: [enquire.org.uk/what-is-additional-support-for-learning](http://enquire.org.uk/what-is-additional-support-for-learning)

**Wales**

**Access to Education and Support for Children and Young People with Medical Needs (2010)**

The aim is to minimise the disruption to normal schooling by encouraging the use of individual healthcare plans, with all children and young people with complex health needs having an identified key worker or care co-ordinator. The guidance also covers administration of medications, provision for exams, school-trips, sports and school transport.

For more information, see: [learning.gov.wales/resources/browse-all/supporting-learners-with-healthcare-needs](http://learning.gov.wales/resources/browse-all/supporting-learners-with-healthcare-needs)

**Northern Ireland**

**Supporting Pupils with Medication Needs (2008)**

The school should work with healthcare specialists, parents and education staff, to draw up a policy (including a Medication Plan and Protocol for each child who needs it) to make sure children with medication needs get care and support whilst in education. Training should be available to staff supporting the pupil with their medication.

For more details, see: [education-ni.gov.uk/articles/support-pupils-medication-needs](http://education-ni.gov.uk/articles/support-pupils-medication-needs)

**Special Educational Needs and Disability Order or SENDO (2005)**

Covers how the Disability Discrimination Act (1995) should be applied in practice to make sure that pupils with disabilities are not given less favourable treatment.

See the nidirect website: [nidirect.gov.uk/articles/learning-and-your-rights](http://nidirect.gov.uk/articles/learning-and-your-rights)

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**OTHER USEFUL ORGANISATIONS**

**Contact a Family**

Website: [www.cafamily.org.uk](http://www.cafamily.org.uk)

Helpline: 0808 808 3555

Provides information, advice and support to the parents of disabled children.

**Crohn's in Childhood Research Association (CICRA)**

Telephone: 020 8949 6209

Website: [www.cicra.org](http://www.cicra.org)

Email: [support@cicra.org](mailto:support@cicra.org)

**ERIC (Education and Resources for improving Child Continence)**

Website: [www.eric.org.uk](http://www.eric.org.uk)

Helpline: 0845 370 8008 (Calls to helpline will cost 9.6p per minute plus service provider charge.)

**IA (The Ileostomy and Internal Pouch Support Group including Young IA for children and young people)**

Telephone: 0800 018 4724

Website: [www.iasupport.org](http://www.iasupport.org)

Email: [helplines@iasupport.org](mailto:helplines@iasupport.org)



**PINNT (including Half Pinnt) – Patients on Intravenous or Nasogastric Nutrition Therapy**

Website: [www.pinnt.com](http://www.pinnt.com)

**IPSEA (Independent Parental Special Education Advice)**

Website: [www.ipsea.org.uk](http://www.ipsea.org.uk)

Telephone: 0800 018 4016

Legal based advice to families who have children with special educational needs.

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**HELP AND SUPPORT FROM CROHN'S AND COLITIS UK**

You can download all our information sheets and booklets from our website: [www.crohnsandcolitis.org.uk](http://www.crohnsandcolitis.org.uk). You can also request them free of charge from our office – call or email our helpline.

**Crohn's and Colitis UK Helpline:** Our helpline is a confidential service providing information and support to anyone affected by Crohn's Disease, Ulcerative Colitis and other forms of Inflammatory Bowel Disease (IBD). Our team can:

- help you understand more about IBD, diagnosis and treatment options
- provide information to help you to live well with your condition
- help you understand and access disability benefits
- be there to listen if you need someone to talk to
- put you in touch with a trained support volunteer who has personal experience of IBD

Call us on 0300 222 5700 or email [helpline@crohnsandcolitis.org.uk](mailto:helpline@crohnsandcolitis.org.uk)

Monday, Tuesday, Wednesday and Friday – 9 am to 5 pm

Thursday – 9 am to 1 pm

**It may be useful for you to let any child, young person or family affected by IBD know about our services:**

**Parent to Parent** is a confidential telephone service for parents of children and young people up to and including the age of 21. It is staffed by trained volunteers all of whom have had a child with IBD. Appointments can be arranged by contacting the Information Service (see above).

**The Family Network** offers fun and informal activities for children with IBD up to and including the age of 18 and their families, and arranges Fun Days for the families and children to meet. It can be reached via the Crohn's and Colitis UK website.

**Crohn's and Colitis UK Facebook Forum** is a closed-group community on Facebook, which is for everyone affected by IBD: [www.facebook.com/groups/CCUKforum](http://www.facebook.com/groups/CCUKforum)

**Extra Financial Help**

At Crohn's and Colitis UK we offer small Educational and Vocational Grants for people with IBD. Details of these are on the Personal Grants pages of our website. We can also help with information about state benefits, including DLA for Children Under 16 and Personal Independence Payment (PIP).



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Crohn's and Colitis UK publications are research based and produced in consultation with patients, medical advisers and other health or associated professionals. They are prepared as general information on a subject and are not intended to replace specific advice from your own doctor or any other professional. Crohn's and Colitis UK does not endorse or recommend any products mentioned.

Crohn's and Colitis UK is an accredited member of the Information Standard scheme for Health and Social care information producers. For more information see [www.crohnsandcolitis.org.uk](http://www.crohnsandcolitis.org.uk) and the Information Standard website: [www.england.nhs.uk/tis](http://www.england.nhs.uk/tis)

We hope that you have found this leaflet helpful and relevant. If you would like more information about the sources of evidence on which it is based, or details of any conflicts of interest, or if you have any comments or suggestions for improvements, please email the Publications Team at [publications@crohnsandcolitis.org.uk](mailto:publications@crohnsandcolitis.org.uk). You can also write to us at Crohn's & Colitis UK, 1 Bishops Square, Hatfield, Herts, AL10 9NE or contact us through our **Helpline: 0300 222 5700**.

### ABOUT CROHN'S & COLITIS UK

We are a national charity established in 1979. Our aim is to improve life for anyone affected by Inflammatory Bowel Diseases. We have over 33,000 members and 50 Local Networks throughout the UK. Membership costs start from £15 per year with concessionary rates for anyone experiencing financial hardship or on a low income.

This publication is available free of charge, but we would not be able to do this without our supporters and members. Please consider making a donation or becoming a member of Crohn's and Colitis UK. To find out how call **01727 734465** or visit [www.crohnsandcolitis.org.uk](http://www.crohnsandcolitis.org.uk)



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