

Children and young people with IBD: a guide for schools

Introduction

In the UK, one person in 250 has Crohn's Disease or Ulcerative Colitis, the two most common forms of Inflammatory Bowel Disease (IBD). These distressing illnesses can start in childhood: although IBD is rare in children under 2, the incidence increases substantially from the age of 10, and increases further among young adults. There are now approximately 5 new cases per 100,000 children under 16 each year. A primary school teacher may only occasionally have a child with IBD in their school, but secondary school teachers are quite likely to have at least one pupil in their school with the disease.

This guide has been produced to provide school staff with some general information about IBD and its likely physiological and psychological effects. It has been written with the help of parents of children with the condition and includes some of their comments. If you would like further copies or additional information, please contact us at Crohn's and Colitis UK, or see our website: www.crohnsandcolitis.org.uk.

A summary sheet is included on page 10. You can help by photocopying and circulating this to everyone involved with the wellbeing of pupils with IBD.

What are Ulcerative Colitis (UC) and Crohn's Disease?

Ulcerative Colitis is inflammation of the lining of the colon (large bowel) which causes ulceration and bleeding. In **Crohn's Disease** the walls and lining of the digestive tract become inflamed, swollen and ulcerated. The disease can occur anywhere between the mouth and the anus, but most commonly affects the small bowel or the colon.

These are lifelong illnesses which may have periods of remission when there are few symptoms, but also periods of relapse when the disease is active and the symptoms much harder to cope with. There is no cure at present.

What they are not...

- They are **not** infectious.
- They are **not** the same as the more common condition of Irritable Bowel Syndrome (IBS). IBS has some similar symptoms but does not cause inflammation and requires quite different treatment.
- They are **not** fatal.

What causes UC and Crohn's?

Although there has been much research, the cause of IBD is still uncertain. However, over the past few years there have been major advances, particularly in genetics. Researchers now believe that IBD is caused by a complex interaction of factors: the genes a person has inherited and an abnormal reaction of the immune system to certain bacteria in the intestines, triggered by something in the environment.

Viruses, bacteria, the use of antibiotics, diet, and stress have all been suggested as environmental triggers, but there is no definite evidence that any one of these is the cause of IBD.

What are the symptoms?

The common symptoms are:

- an urgent need to go to the toilet
- diarrhoea
- passing blood with the stools
- severe abdominal pain
- extreme tiredness
- nausea
- loss of appetite
- weight loss and failure to grow

Some children may also suffer from joint pains, eye problems, skin rashes, and mouth ulcers.

What can be the impact of having IBD?

Delays in development

Because inflammation in the bowel can affect both appetite and the absorption of nutrients, it can cause delays in normal growth and development. This means children and young people with IBD may be smaller and seem younger than their peers. Puberty may be delayed and some teenagers may lag behind their peers in sexual development.

Effects of treatment

IBD usually requires life-long management and its treatment may have unpleasant side effects.

Drug treatment often includes corticosteroids (steroids) to reduce inflammation. Unwanted side-effects of this type of drug, especially at high initial doses, can include:

- significant weight gain
- roundness of the face
- acne
- moodiness
- impaired concentration
- temporary slowing down of growth.

NB These steroids are not the same as anabolic steroids sometimes used by athletes.

Other drugs that may be given for IBD include anti-inflammatory drugs, immunosuppressants, and, more recently, biologics or anti-TNF drugs. Some of these can also have unwanted side effects such as

- headaches
- nausea or flu-like symptoms
- greater risk of infections because of a suppressed immune system.

Children and young people with Crohn's Disease are often put on dietary treatment, especially when first diagnosed.

This involves taking a specially formulated liquid feed that contains all the nutrients needed and can be easily absorbed. Usually, nothing other than the diet and water are allowed for weeks at a time. When food is reintroduced, the liquid diet may still be given as a supplement. Some children and young people can find it difficult to drink the feed, so may take it via a nasogastric feeding tube instead. This is a fine plastic tube which is inserted through the nose down into the stomach. Or, they may have a percutaneous endoscopic gastrostomy (PEG) feeding tube, which is inserted directly into the stomach through the wall of the abdomen. Once in place these tubes can remain for many weeks. Sometimes the high concentration of nutrients in the liquid diet can cause nausea, headaches, and a feeling of light-headedness.

Hospitalisation

There may be times when a child or young person experiencing a severe acute flare-up of IBD needs treatment in hospital, sometimes lasting several weeks. In very severe cases badly affected parts of the bowel may need to be removed by surgery. This may involve an ileostomy (surgery to create an opening from the small bowel onto the surface of the abdomen). The child or young person then has to wear a stoma bag to collect waste (faeces). Ileostomies may be temporary but can be permanent.

Psychological effects

It can be very hard for children, particularly adolescents, to cope with the embarrassment of their disease. They dread having to rush for the toilet, having an accident, creating smells, and, as a result, being ridiculed.

Being on dietary treatment can also be difficult. The psychological effects of not being able to eat can be very significant, especially when the child or young person is surrounded by temptation and bombarded by food advertising. It can also be socially isolating if they cannot eat

the same foods as their friends. Even for those not on an exclusive liquid diet, meals can become something to fear and avoid if food is associated with symptoms such as cramping pain, vomiting and diarrhoea.

Young people with IBD often feel distressed about being smaller, thinner and less developed than their classmates. Or, if they are taking high dose steroids for their treatment, they may be worried about putting on weight and becoming fatter, round-faced and spotty.

They may feel even more isolated and out-of-step with their peers if they miss a lot of school or are unable to join in sports and activities. It can be hard to cope with the unpredictability of IBD, which might mean feeling great one day, and utterly drained and exhausted the next. Also, appearances can be deceptive: a child or young person with IBD may not look that unwell even on a day they are feeling awful, especially if they are on steroids.

Teenagers with IBD may be at particular risk if they show the rebellious behaviour common to many adolescents. For example, they may be in denial about their illness, show anger, neglect their diet or refuse to take medication. The unpredictability of relapses, the kinds of symptoms experienced, and the adverse effects of IBD drugs, can all lead to feelings of loss of control and increased risk of depression and anxiety. When trying to cope with chronic pain and exhaustion they may be unable to concentrate, feel depressed and perhaps, in extreme cases, have suicidal thoughts. Although stress is not a cause of IBD, many doctors have observed that stress is associated with relapses of the condition, often at exam time.

For more information on IBD in children, see our booklet *IBD in children: a parent's guide*.

IBD and school legislation

There are a number of laws which may be relevant to a school's responsibility toward its pupils with IBD.

For example, children with IBD may be covered by the Equality Act 2010. This act includes 'hidden' impairments, such as incontinence, when these are long-term and substantially affect the child's ability to carry out normal day-to-day activities.

From 2006 The Disability Equality Duty (DED) has required schools to take a proactive approach in promoting disability equality and eliminating discrimination. This means, for example, promoting positive attitudes towards disability, stopping disability related bullying, involving disabled pupils in identifying their needs, and making reasonable adjustments to prevent them from being placed at a substantial disadvantage, even if this requires more favourable treatment.

All schools, except in Northern Ireland, are also required to publish a Disability Equality Scheme to show how the school is meeting this duty.

The Equality Act 2010 contains provisions for a new single public sector equality duty which combines disability related duties with those relating to other equality areas such as gender and race. This is due to come into effect during 2011. Up-to-date guidance on this is available from the Equality and Human Rights Commission website. (See *Further Information*.)

Children with IBD may also be classified as having special educational needs, as a child with any disability that prevents them from making use of educational facilities is considered to have a learning difficulty. Particularly during periods of active disease a child with IBD may need special provisions to be made, which could include involving the Special Educational Needs Co-ordinator (SENCO).

The Department for Education and its predecessor, the Department for Children, Schools and Families (DCSF, formerly DfES) recommends drawing up an individual health care plan in these cases.

The Education Act 1996 requires that arrangements are made for children who due to illness would not otherwise receive suitable education. Schools also have legal responsibilities towards pupils with medical needs which could apply to children with IBD.

For more information on guidance on meeting these legal responsibilities see *Further Information* at the end of this leaflet.

How can schools help?

Awareness and understanding

Being aware of the symptoms and possible impact of having IBD is a key starting point. This can really help schools to implement policies which encourage the child or young person with the condition to enjoy all aspects of school life.

Most children and young people with Crohn's Disease or UC will have periods of remission and many are able to attend school for most of the time. Some may not need much in the way of extra help and support except when having a relapse or 'flare up'. IBD is a complex, individual condition however, so it is important to discuss the pupil's particular needs with them and their parents, and possibly with health professionals involved in their care.

You may also find it helpful to access some of the wide range of additional information on IBD available from us at Crohn's and Colitis UK – our contact details are given at the end of this leaflet.

Some parents may find it difficult to approach the school and may particularly benefit from teacher and school staff support and understanding. They may still

be struggling to cope with the shock of finding out about their child's diagnosis or with the additional pressures of living with a chronic illness in the family.

There may also be siblings at the school who could feel resentful of all the attention on the sibling with IBD. An understanding attitude towards the whole family and the way they are dealing with the impact of having a sibling/child with IBD can help each one of them.

Teacher liaison

If possible appoint a named teacher or other suitable person to act as a liaison between the school, the parents and the young person with IBD, especially in secondary school or where there is not a permanent class teacher.

This designated person can discuss issues of concern with the parents and pupil, develop a health care plan, notify all the relevant people, and ensure that action is taken to meet the young person's needs. They can also review ongoing or changing needs, ideally at least once a year, and draw up procedures to pass on the needs information, for example when the child changes classes or moves from primary to secondary school.

Key issues

The following issues may be of concern:

- **Toilet needs**

The need to go to the toilet can be frequent and so sudden and urgent that an accident could easily happen if there is any delay in getting there. It is helpful if the child or young person can sit close to the door and is allowed to leave and return to the room discreetly and without question. Some schools provide a permanent 'lesson pass' allowing such absences from the classroom.

Using communal toilet areas can be very embarrassing for children and young people with these illnesses - and may be impossible if the toilets are kept locked at

certain times of day. Please consider allowing them to use staff toilets if possible (being given a key if necessary).

A locker for toilet kit and a change of clothes could also be very useful.

- **Lateness**

An urgent need for the toilet (particularly after food) may lead to late arrival at school or lessons. Pupils may also be late for classes if there is some distance to be covered between rooms for different lessons. Extreme tiredness or joint pains can slow a pupil down. An understanding attitude towards late arrival can help avoid additional embarrassment.

- **Medication**

Pupils with IBD may need to take prescribed drugs at certain times of day, for example before meals. All schools should have a clear policy on the administration of medicines while at school. Good practice encourages pupils who can be trusted to do so to manage their own medication from a relatively early age. They may then only need supervision. A decision on whether pupils can carry and take their own medication should involve the young person and the parents.

- **Eating and drinking while at school**

A child or young person with IBD may have difficulty in eating a normal size meal – perhaps because they feel full after eating only a little food, or because of pain or needing to go to the toilet during the meal. To make sure that they eat enough food to meet their needs, their doctor or dietitian may advise eating small amounts regularly of as wide a range of foods as possible, perhaps supplemented by proprietary liquid meals. This may mean pupils with IBD will need extra meal breaks. They may also need to avoid certain foods and to drink extra water.

- **Dietary treatment at school**

Some pupils with IBD may be on dietary treatment as described earlier. If a pupil has a nasogastric or PEG tube they may feel embarrassed or anxious about attending school with the tube in place and may need additional support and/or practical help.

“The school is very good when he is being drip fed. He gets help with the back pack and looking after his tube. The school provided a fridge when our son was liquid fed for 8 weeks.”

- **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 the child or young person feels so unwell that they would benefit from being sent home. On other days, however, a brief period of rest or a prescribed painkiller may enable them to carry on. If possible, teachers should allow the pupil to decide whether to go or stay, depending on their symptoms and whether someone will be at home.

- **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. At such times an extended deadline would be most helpful. Studying for exams may also be very difficult and the pupil may need extra guidance and emotional support.

- **PE and sport**

Strenuous physical exercise can trigger an urgent need to go to the toilet or joint pains. Even mild exertions may be too much at times when a child or young person is feeling exhausted, suffering severe stomach pain, or is recovering from surgery. On good days, however, they may feel able to participate fully.

Team games can be particularly problematic: some children or young people, keen to be part of the team, may try to push themselves beyond their limit 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 and to treat them the same as other pupils as far as this is possible.

- **Missing school**

Although many young people with IBD can attend school most of the time, there may be times when they do have to miss school if, for example, they are seriously unwell with a flare up, or need hospital treatment. Most do not like to feel forgotten or abandoned by the school when they are ill. Encouraging classmates to stay in touch by phone or email, or by sending cards, can help them feel less isolated.

If a pupil is resting at home they may be able to cope with most school work. At other times (such as when in hospital), they may not be able to manage as much, but will always benefit from contact and reassurance about catching up.

Providing notes on missed lessons and setting work by email could help them to catch up when they do feel better. If a child or young person does not have the use of a home computer, your school may be able to arrange the loan of a laptop and software. Your local education authority should have a policy in place to enable the continuance of education if a pupil is away from school for a prolonged period of time or is repeatedly absent because of illness.

“They need to understand that my son cannot physically get to school. But, his mind is OK and he can work at home.”

- **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, as is usually the case. It often helps if the pupil can sit close to the door nearest the toilets and to arrange in advance who will escort them to the toilet if they need to go urgently. Some may also need extra time if they have extra breaks or are suffering from fatigue. 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.

- **After-school activities**

A child or young person with IBD may be reluctant to join in after-school activities, however interested they may be, because they are unsure about committing themselves. Any special encouragement or consideration that can be given will help to support their full involvement in school life. For example, lifts home with a school-friend could make a real difference for a pupil who finds using buses difficult.

Outings

Outings can be a nightmare for anyone with IBD if there are no toilet facilities on the train or coach, or none readily available during the trip. Some venues can also be difficult for someone with IBD. It helps if such needs can be thought about in advance and, for example, the pupil can have an aisle seat at a cinema or in a lecture theatre setting. Where toilet facilities cannot be guaranteed, it should be understood if they opt to miss the trip.

Because IBD can be so unpredictable, if possible have arrangements so that students can decide whether or not to join a trip on or close to the day itself - without having to commit themselves financially beforehand.

Automatic exclusion from all trips could be very hurtful and might possibly be challenged under disability discrimination legislation.

“During a bad flare-up at primary school some home tuition was provided, which was very helpful. However, sadly, the school has also caused terrible emotional damage through ignorance, including refusing to take my daughter on school trips with other pupils, which upset her terribly.”

- **Bullying**

If a child or young person with IBD seems withdrawn or socially isolated it could be because other children are making them unhappy by bullying them or picking on them because of their illness.

“Bullying started when my daughter was on steroids: they were calling her ‘gerbil face!’”

One useful approach to help counteract this might be to give information about IBD, possibly by an expert, to a small group or the whole class during a PSHE or citizenship lesson. This could help the child’s peers to be more understanding about the symptoms and may also make the pupil with IBD more confident about sharing their feelings. The agreement of the child and parents would be essential for this.

- **Respect and boundaries**

No child or young person likes to be different. They may want to keep the nature of their illness private and this should be respected. Most also want to be treated in the same way as any other pupil and to feel that achievements are expected of them, not that they are disregarded. At the same time, as with any child or young person, those with IBD

need clear boundaries to their behaviour. If they behave badly because of anger about their situation it is probably more helpful to acknowledge their feelings while remaining firm, rather than to ignore or condone their behaviour.

Additional Support

It is helpful if the child or young person with IBD feels able to go to their liaison person whenever they have any concerns or worries. Some may also benefit from the support of the school counsellor, if one is available, especially if they have feelings of loss and/or anger or are in denial about their illness. Our leaflet *Counselling for IBD* gives further details on how to find counsellors with experience of working with people with IBD.

Some children and young people will have a specialist IBD nurse as part of their hospital IBD team who may be willing to come into the school and discuss the condition generally and suggest ideas.

Other support provided by Crohn's and Colitis UK

The Crohn's and Colitis UK Information Line: 0845 130 2233, is open Monday to Friday 10am-1pm. There is an answerphone service outside these hours, or you may email info@crohnsandcolitis.org.uk. Information staff will help with any IBD related queries.

Crohn's and Colitis Support: 0845 130 3344, open Monday to Friday 1pm-3.30pm and 6.30pm-9pm. This is a supportive listening service staffed by trained volunteers with personal experience of IBD.

Parent-to-Parent is a Crohn's and Colitis UK service which offers parents of children with IBD confidential support and information by phone, from trained volunteers who are themselves parents of children with IBD. Call the Information Line for an appointment.

Smilie's Network is a special Group within Crohn's and Colitis UK for families with a child or young person who has IBD. They arrange activities for both children and parents. For more details see: www.groups.crohnsandcolitis.org.uk/smilie_snetwork

Crohn's and Colitis UK also has **Local Groups** around the UK that sometimes offer meetings for parents as well as information talks which parents may find helpful. See our website for more details.

Part of our information service also includes help and advice about claiming benefits such as Disability Living Allowance. Parents of children under 16 with IBD can sometimes claim DLA on their behalf. We also offer small Educational and Vocational Grants for young people with IBD between the ages of 15 and 25. For more details call the Information line or see our website www.crohnsandcolitis.org.uk

Other useful organisations

Crohn's in Childhood Research Association (CICRA)

Parkgate House, 356 West Barnes Lane, Motspur Park, Surrey KT3 6NB
☎ 020 8949 6209. Fax: 020 8942 2044
Website: www.cicra.org
Email: support@cicra.org

IA (The Ileostomy and Internal Pouch Support Group)

Pevevill House, 1-5 Mill Road, Ballyclare, Co Antrim, BT39 9DR
☎ 0800 018 4724
Website: www.iasupport.org
Email: info@iasupport.org
Young IA Co-ordinator: Peter Laflin –
Email: peter.laflin@iasupport.org
Young ia gives support to young people undergoing an ileostomy or internal pouch operation, before and after surgery.

PINNT (including Half Pinnt) – Patients on intravenous or nasogastric nutrition therapy

PO Box 3126, Christchurch,
Dorset BH23 2XS

Website: www.pinnt.com

Email: pinnt@dial.pipex.com

Half Pinnt supports families caring for a child on nutrition therapy.

ERIC (Education and Resources for improving Child Continence).
34 Old School House, Britannia Road, Kingswood, Bristol BS15 8DB
Website: www.eric.co.uk
Helpline: 0845 370 8008
ERIC is campaigning for better toilets for pupils and has set up a website www.bog-standard.org which includes information on how teachers can help.

Further information

For updated information following the change in government in 2010 see the new **Department for Education** website <http://www.education.gov.uk/>. A number of useful guides from the Department for Education and other documents are also available online at <http://www.teachernet.gov.uk>, (0870 000 2288 9am-5pm weekdays).

The following may be especially helpful: **Managing Medicines in Schools and Early Years Settings (2005)**. This guide offers advice on developing policies on managing medication in schools and on drawing up an individual health care plan to support pupils with medical needs.

Access to education for children and young people with Medical Needs. (2002). This sets out minimum national standards for the education of children and young people unable to attend school because of medical needs

The **Equality and Human Rights Commission (EHRC)** has produced guides on the Disability Equality Duty

(DED) and on the 2010 Equality Act, including guidance specifically for education providers such as schools. These are available from the website: www.equalityhumanrights.com . Helpline numbers are also listed on this site.

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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 with suggestions on how to manage particular situations, but they 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.

We hope that you have found the information helpful and relevant. We welcome any comments from readers, or suggestions for improvements. References or details of the research on which this publication is based, and details of any conflicts of interest, can be obtained from Crohn's and Colitis UK at the address below. Please send your comments to Helen Terry at Crohn's and Colitis UK, 4 Beaumont House, Sutton Road, St Albans, Herts AL1 5HH, or email h.terry@crohnsandcolitis.org.uk

Crohn's and Colitis UK is the working name for the National Association for Colitis and Crohn's Disease (NACC). NACC is a voluntary Association, established in 1979, which has 30,000 members and 70 Groups throughout the United Kingdom.

Membership of the Association costs £12 a year. New members who are on lower incomes due to their health or employment circumstances may join at a lower rate. Additional donations to help our work are always welcomed.

A summary of how staff can help support children with IBD

What is IBD?

The two most common forms of Inflammatory Bowel Disease (IBD) are Ulcerative Colitis and Crohn's Disease. These are life-long chronic conditions which can cause severe stomach pain, an urgent need to use the toilet, diarrhoea, extreme tiredness, nausea and loss of appetite. IBD can also delay growth and cause extreme thinness. Some children and young people with IBD also have joint pains, eye problems and mouth ulcers. Symptoms fluctuate and periods of remission can be followed by acute 'flare ups'.

Treatment for IBD often includes courses of drugs which can cause excessive weight gain, a moon-face, spottiness and mood swings. Some children are treated by being put on exclusive liquid diets, and may have a feeding tube. IBD can be very embarrassing to a child or young person and very painful, both physically and psychologically.

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 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 embarrassment about their condition and their need for privacy; they should decide how much other pupils are told.
- Try to be alert for bullying from others.
- Let them judge for themselves how much sport/PE or after-school activities they can join in - but don't stop them trying whatever they want to try.
- Don't exclude pupils with IBD from school trips: talk to them about their needs and try and arrange to meet these, eg 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, don't rush to send them home – sometimes they may be able to continue after a rest.
- If they have to have time off, either at home or in hospital, encourage the class to keep in touch, for example with cards and phone calls or by email.
- Do not automatically wait for them to return to school before offering schoolwork. They may be able to do some work at home and would like to keep up with others in their class. For example, provide notes on lessons and arrange for work to be set by email.
- Arrange a liaison teacher for the child/young person, their parents and other teachers to talk to.
- Keep in touch with parents about their child's ongoing or changing needs. If possible, an individual health care plan should be drawn up for each child/young person, which can be passed on as they move up the school.
- If further information would be helpful, contact the **Crohn's and Colitis UK Information Line: 0845 130 2233, open Monday to Friday 10am-1pm.** There is an answerphone service outside these hours, or you may email info@crohnsandcolitis.org.uk.
- This and all our other information sheets can be downloaded from: www.crohnsandcolitis.org.uk