



Children and young people with IBD: a guide for schools

Introduction

One person in four hundred has Crohn's Disease or Ulcerative Colitis – together called Inflammatory Bowel Disease (IBD). These distressing illnesses occasionally start in young children, but the incidence increases substantially from the age of 10 and increases further among young adults. Overall the incidence up to age 16 is higher than was previously thought and there are approximately 5 new cases per 100,000 children 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.

Some knowledge about the physical and psychological effects of IBD can help you to have a positive impact upon the potential achievements and happiness of those children and young people who are affected.

A summary sheet is included on page 10. You can help by photocopying and circulating it to everyone involved in 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. They are lifelong fluctuating illnesses with unpredictable periods of relapse and remission. Even during remission there may still be some symptoms. There is no cure at present.

What they are not...

- They are **not** infectious.
- They are **not** the same as the more common adult condition of Irritable Bowel Syndrome (IBS).
- They are **not** fatal.

What causes UC and Crohn's?

The cause or causes are not yet known. Researchers believe IBD may be caused by an abnormal reaction of the immune system to intestinal bacteria, combined with predisposing genetic factors and environmental triggers.

What are the symptoms?

The common symptoms are:

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

Some children may also suffer from:

- pains in their joints that can make moving about difficult
- eye problems
- mouth ulcers
- skin rashes

What can be the impact of having IBD?

Delays in development

Inflammation in the bowel can upset both a child's and young person's appetite and the absorption of nutrients and so affect normal growth. This means children and young people with IBD may appear younger and smaller than their peers. Feeling different can be very difficult and they may find themselves excluded from social activities. This can be particularly hard for teenagers when puberty is delayed and they lag behind their peers in sexual development.

Effects of treatment

IBD usually requires life-long treatment, which can have unpleasant side effects. Treatment often includes corticosteroids to reduce inflammation. Unwanted side-effects of this drug, especially at high initial doses, are often:

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

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

Other unwanted side effects from various drugs used for treatment may include:

- headaches
- nausea
- flu-like symptoms
- risk of infections because of suppressed immune system

For children and young people with Crohn's the usual first treatment is dietary. This takes the form of a liquid diet that can be easily absorbed and contains all the nutrients needed. Usually, nothing other than the diet and water are allowed for weeks at a time. When food is reintroduced the liquid diet is given as a supplement.

If there is any difficulty drinking the feed, they may take it via a tube inserted through the nose down into the stomach. Once in place the tube The high concentration of nutrients in the feed sometimes causes:

- nausea can remain for many weeks.
- headaches
- a feeling of light-headedness

Hospitalisation

There may be times when a child or young person experiencing a severe acute flare-up of disease 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. Surgery sometimes includes forming an ileostomy (an opening of the small bowel onto the surface of the abdomen), which may create further problems.

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, smells and any resulting ridicule.

The psychological effects of not being able to eat can be very significant, with constant temptation and bombardment by advertisements. It can be socially isolating if they can't join in with their friends having a burger or other 'fast food'. Meals may become something to fear and avoid when food is associated with symptoms, particularly cramping pain, vomiting and diarrhoea. Young people often feel distressed by being much smaller, thinner and less developed than their classmates; or if they are taking high dose steroids for their treatment, putting on weight and becoming fatter, round-faced and spotty.

They may feel even more isolated and out-of-step with their peers because of missing a lot of school and often being unable to join in activities. Also it is difficult to cope with feeling great one day and utterly drained, pained and exhausted the next. Whilst they may not look unwell, they may in reality be feeling awful.

Teenagers with IBD may be at particular risk if they show the rebellious behaviour common to most adolescents. This may take the form of being in denial about their illness, showing anger, neglecting their diet and refusing to take medication. The unpredictability of relapses, feelings of loss of control from the adverse effects of drugs and from the kinds of symptoms they experience put them at increased risk of depression and anxiety. When chronic pain and exhaustion are ongoing they may be unable to concentrate, feel depressed and in some 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.

IBD and school legislation

Pupils with IBD may be covered by the Disability Discrimination Act 2005 (DDA). The 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. Those 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. This may include involving the Special Educational Needs Co-ordinator (SENCO).

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

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

The new Disability Equality Duty (DED) requires schools to have a more 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. Schools, except in Northern Ireland, are now required to publish a Disability Equality Scheme.

For guidance on meeting legal responsibilities see Further Information below.

How can schools help?

An awareness of the symptoms and impact of having IBD can help schools to implement an Individual Education Plan that allows the child or young person with the condition to enjoy all aspects of school life. IBD is a complex, individual condition 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.

Some parents may find it difficult to approach the school and may benefit from a teacher's support and understanding. They may still be struggling to cope with the shock of finding out about their child's diagnosis or struggling with the additional pressures of living with a chronic illness in the family. There may also be siblings at your school who may feel resentful of all the attention on the sibling with IBD and then feel guilty. They may misbehave to seek attention or may withdraw into themselves. An understanding attitude of teachers towards the whole family dealing with the impact of a chronic illness helps each one of them.

Teacher liaison

Appointing a named person to act as a liaison between the school, the parents and the young person is particularly helpful, especially in secondary school or where there is not a permanent class teacher. A 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. A review of ongoing or changing needs is helpful at least once a year. When a pupil changes classes or moves from primary to secondary school, it is helpful if procedures are in place to pass on information about their needs. Both teachers and the pupil may benefit if there is someone particular they can go to for support. They may be anxious about school work, have problems with their peers or feel a particular teacher isn't being understanding. If counselling is available in school, this can be helpful for the child or young person in such situations and also for those who become withdrawn, have feelings of loss and/or anger and those in denial of their illness.

The following issues are likely to 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 absence from the classroom.

Using communal toilet areas can be embarrassing for children and young people with these illnesses and may be impossible if they are kept locked at certain times of day. Perhaps they can be allowed to use a staff toilet (being given a key if necessary). It

may also be helpful if they can have the facility of a locker by their toilet to keep spare clothes and a washing kit in case of accidents.

Medication

A pupil may need to take prescribed drugs at certain times of day, for example before meals. A clear policy on the administration of medicines should be available to parents and young people. 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 between breaks

Very often a child or young person with IBD will have difficulty in eating a normal size meal. This may be because they feel full when very little food has been eaten, 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, the doctor or dietitian may advise eating small amounts regularly with as wide a range of foods as possible, sometimes supplemented by proprietary liquid meals. Foods to avoid are those that the child or young person and parents have identified as making the symptoms worse. Extra water may also be needed, especially if they are on a special liquid diet. At times the liquid feed is the only food taken for several weeks. Occasionally it is given through a nasogastric or a percutaneous endoscopic gastrostomy (PEG) feeding tube. The first is a fine tube passed through the nose down into the stomach and the latter is inserted directly into the stomach under sedation. Once in place the tube can remain for many weeks.

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.

Lateness

An urgent need for the toilet (particularly after food) may lead to late arrival at school or lessons. Lateness may also result if there is some distance to be covered between rooms for different lessons. Extreme tiredness or joint pains may slow a pupil down.

Feeling unwell at school

A child or young person may feel tired or have stomach ache so often that it may not be best for them to be consistently sent home early. A brief period of rest or a prescribed painkiller may enable them to carry on. However, pain and exhaustion affect concentration and teachers should allow the pupil to decide whether to go or stay, depending on 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. Team games can be particularly problematic. No one likes to feel they are spoiling their team's chances and some children or young people may push themselves beyond their limit so as not to let anyone down. But on good days they may really feel

able to join in. It is best to let the pupil judge what they can manage and to treat them normally so far as possible.

Missed school

A child or young person may miss school because of medical and hospital appointments, being ill at home or hospital admissions. On the whole they do not want to feel forgotten or abandoned by the school when they are ill. Encouraging other classmates to stay in touch by email, with a get-well card or with a phone call can be helpful too. If a pupil is resting at home they may be able to cope with most school work. At other times (eg in hospital), they may not be able to manage as much, but will always benefit from contact and reassurance about catching up. Organising for notes to be taken or photocopied of missed lessons and setting work by email could help them to catch up when they are better. 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. His mind is OK and he can work at home. In 3 years my son's attendance is far less than 50% and I am beside myself in despair with the school's seeming reluctance to be involved with him.

Exams

The fact that exams have to take place at fixed times puts pressure on children and young people who have a fluctuating and unpredictable illness. They may also have particular problems with morning exams if their bowels are most active then, as is often the case. It is helpful to seat the pupil 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. Providing extra time would also be helpful. 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 may not join in after-school activities, however interested they may be, because they are unsure about committing themselves. They may also be unsure about whether intermittent attendance is acceptable. Any special encouragement or consideration that can be given will help to support their full involvement in school life. Lifts home with a school-friend may be helpful if they can be arranged.

Outings

Outings can be a nightmare for a child or young person if there are no toilet facilities on a coach or none readily available during the trip out. The pupil may choose an aisle seat at a cinema or a talk to reduce anxiety, but where toilet facilities can't be guaranteed it should be understood if they opt to miss the trip. Where possible, it is helpful if they can decide on or close to the day if they are able to come and don't have to commit themselves financially beforehand.

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. It may be helpful to give information about IBD, possibly by an expert, to a small group or whole class during a PSHE or citizenship lesson. This could help their peers to be more understanding about the symptoms and may make the pupil with IBD more confident to share their feelings. The agreement of the child and parents would be essential for this.

Bullying started when my daughter was on steroids, calling her "gerbil face"

Respect and understanding

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. They should feel that achievements are expected of them, not that they are disregarded. 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 lot, acknowledging their feelings while remaining firm is better than ignoring or condoning their behaviour.

Outside help

Schools sometimes welcome the help of someone who is an independent expert but is uninvolved emotionally with a particular child or young person. The National Association for Colitis and Crohn's Disease (NACC) will assist with information or a local contact whenever possible. Some children and young people also have a specialist IBD nurse who may be willing to come and discuss the condition generally and suggest ideas. The pupil's parents will know if one is available.

NACC has produced a video/DVD called **Talk About Crohn's** of three young people talking about their experience of growing up with Crohn's Disease. A similar video/DVD for Ulcerative Colitis has one young person and two older people talking about living with this condition. Copies are available for £20 from the NACC website: www.nacc.org.uk.

Support for parents, children and young people

Parent-to-Parent is a NACC service which offers parents confidential support and information by phone from trained volunteers who are parents of children with IBD. Call the NACC Information Line on 0845 130 2233 for an appointment.

Smilie's People is a special NACC Group for families which have a child or young person who has IBD. They arrange activities for both children and parents. For more details see the website: www.smiliespeople.org.uk. NACC also has groups around the UK that sometimes offer meetings for parents as well as information talks which parents may find helpful.

NACC organizes fun days for families with a child or young person up to 16 who has IBD. For further information telephone the NACC Information line on 0845 130 2233.

NACC operates a supportive listening service called **NACC-in-Contact** on **0845 130 3344** run by trained volunteers with personal experience of IBD.

NACC offers Educational and Vocational Grants for young people with IBD between the ages of 15 and 25. Call the NACC Information line on 0845 130 2233 for more details.

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)

Peeverill House, 1-5 Mill Road, Ballyclare, Co Antrim, BT39 9DR

☎ 0800 018 4724 (freephone) or 028 9334 4043 (standard rate) Fax: 028 9332 4606

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, before or 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 is a support group for children and families co-ordinated by parents caring for a child on nutrition therapy.

Further information

The following guides from the **Department for Children, Schools and Families** are available online at www.teachernet.gov.uk/publications or ☎ 0870 000 2288 9am-5pm weekdays.

Managing Medicines in Schools and Early Years Settings This guide offers advice on developing policies on managing medication in schools and drawing up an individual health care plan to support pupils with medical needs.

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

The **Equality and Human Rights Commission (EHRC)** has produced guides on the Disability Equality Duty (DED) which explain what the Duty means and how to produce a Disability Equality Scheme. They are available from the website: www.equalityhumanrights.com or the EHRC Helplines:

EHRC Disability Helpline England:

☎ 08457 622 633 weekdays 9am-5pm except Wednesdays 9am-8pm.

EHRC Helpline Scotland: ☎ 0845 604 5510 weekdays 9am – 5pm.

EHRC Helpline Wales: ☎ 0845 604 8810 weekdays 9am – 5pm.

For information on disability legislation in education in **Northern Ireland:**

Website: www.deni.gov.uk or ☎ 028 9127 9279.

Disability Equality in Education is a non-governmental organisation which provides resources and training for schools on the DED.

Website: www.diseed.org.uk ☎ 020 7359 2855

ERIC (Education and Resources for Improving Childhood Continence)

34 Old School House, Britannia Road, Kingswood, Bristol BS15 8DB

Website: www.eric.org.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.

For more information on any aspect of IBD and for full details about all NACC's publications and services see our website: www.nacc.org.uk or contact our Information Line ☎ 0845 130 2233.

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This document has been prepared by NACC as general information on the subject and is not intended to replace specific advice from health professionals.

The National Association for Colitis and Crohn's Disease (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 for the first year and £10 subsequently. Additional donations to help the work of the Association are always welcomed.



For teachers of a child or young person with Ulcerative Colitis (UC) or Crohn's Disease

A summary of how you can help

UC and Crohn's are inflammatory bowel conditions which can cause severe stomach pain, an urgent need to use the toilet, diarrhoea, extreme tiredness, nausea and loss of appetite. Sometimes there are joint pains that can make moving about painful as well. Symptoms fluctuate; one day a child may be fine, the next day in pain and exhausted.

The disease can delay growth and cause extreme thinness. However, treatment with steroids can cause excessive weight gain, a moon-face, spottiness and mood swings, particularly weepiness. These conditions are very embarrassing to a child and young person and very painful, both physically and psychologically.

Actions that can help:

- Let the child leave and return to the classroom discreetly and without getting permission whenever they need to use the toilet.
- Let them use the staff toilet, for privacy or if other toilets are locked or some distance away.
- Appreciate that they may arrive late at school or for lessons because of urgency to use a toilet or joint pains that have slowed them down.
- Let them judge for themselves how much sport or PE they can join in; but don't stop them trying whatever they want to try.
- Respect their embarrassment about this condition and their need for privacy; they should decide how much anyone in the class is told.
- Try to make special arrangements for them on outings (e.g. an aisle seat at the theatre or cinema or on the coach) and, if possible, use a coach that has a toilet.
- Try to be alert for bullying from others.
- Don't rush to send a child home from school; often, if allowed to rest, they may be able to continue later.
- If they have to have time off, either at home or in hospital, don't automatically wait for them to return before offering schoolwork. Sometimes they need to rest, but may be able to do some schoolwork.
- When they are more ill, they still need contact and reassurance about catching up.
- Organise for notes to be taken or photocopied of any missed lessons or for work to be set by email.
- Encourage classmates to keep in touch by email, with get-well cards or phone calls.
- Arrange a liaison teacher for the child/young person, parent or other teachers to talk to.
- Keep in touch with parents about the child/young person's ongoing or changing needs.
- Be aware of your school's policies on supporting children with medical needs.
- If further information would be helpful, contact the child's specialist nurse or doctor, or the National Association for Colitis and Crohn's Disease (NACC) on **0845 130 2233**.