



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.

“

The school have been fantastic and so supportive of my son, Fergus, and us as a family. When Fergus was diagnosed with Crohn's Disease, I went into school and explained the condition to the teacher, but also to reassure them that it isn't contagious, and just something that we were going to deal with as a family. They were really understanding, and said I could come into school and go as needed.

”

Fiona, mother to Fergus, age 11
Diagnosed with Crohn's Disease in 2010

INTRODUCTION

In the UK, at least one person in 210 has Crohn's Disease or Ulcerative Colitis, the two most common forms of Inflammatory Bowel Disease (IBD). These distressing illnesses can start in childhood, and studies suggest that around a quarter of people with IBD were aged under 16 when they were diagnosed. 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 Inflammatory Bowel Disease (IBD) and its likely physical and psychological effects. It has been written with the help of parents of children with the condition and includes some of their comments.

WHAT ARE ULCERATIVE COLITIS (UC) AND CROHN'S DISEASE?

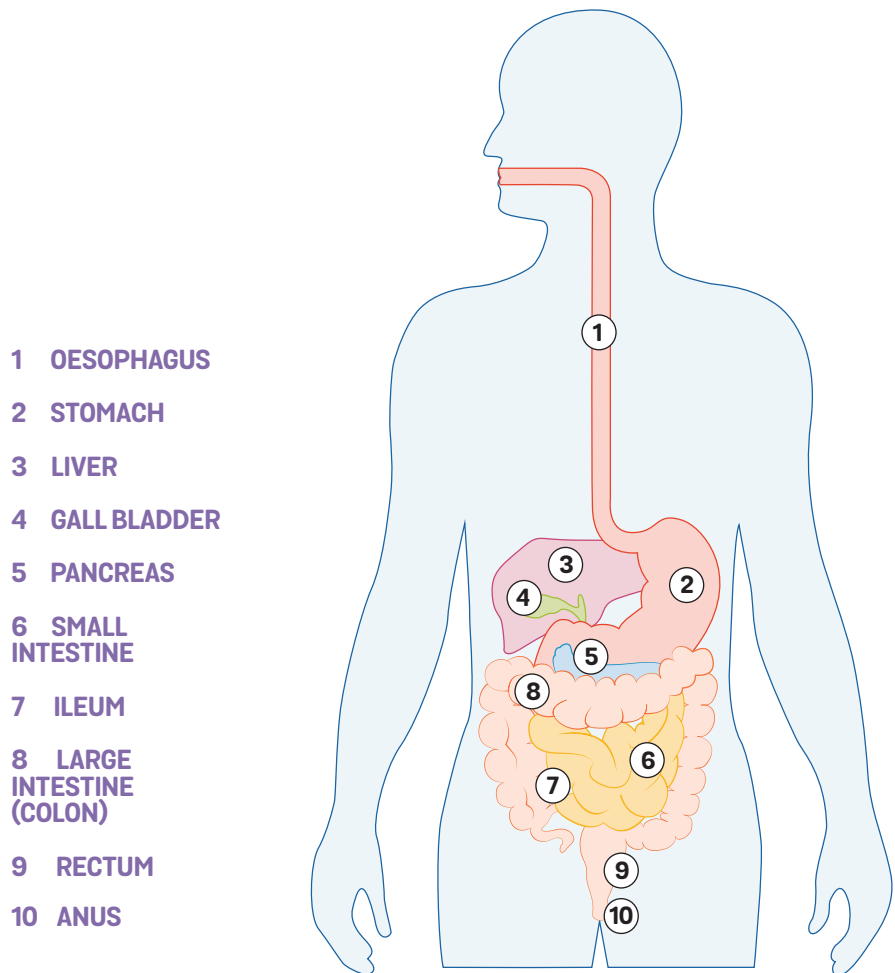
Ulcerative Colitis is inflammation of the lining of the colon and rectum (the large bowel) which causes ulceration and bleeding.

In **Crohn's Disease** the walls and lining of the digestive tract become inflamed, swollen and ulcerated. Crohn's can occur anywhere between the mouth and the anus, but most commonly affects the small intestine (small bowel) or colon.

It is not always possible to distinguish between Crohn's and UC – so some children may be given a diagnosis of **Indeterminate Colitis** or **IBD Unclassified (IBDU)**.

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.

THE DIGESTIVE SYSTEM – AND THE AREAS IBD CAN AFFECT



WHAT THEY ARE NOT...

- They are not infectious or contagious.
- They are not the same as Irritable Bowel Syndrome (IBS). IBS has some similar symptoms to IBD, but is a different condition and is treated differently.
- They are not fatal.

WHAT CAUSES UC AND CROHN'S?

Although there has been much research, the cause of IBD is still uncertain. Many researchers now believe that IBD is caused by a combination of factors: the genes a person has inherited which may predispose them to develop IBD, and then an abnormal reaction of the immune system (the body's protection system) to certain bacteria in the intestines, possibly triggered by something in the environment.

Viruses, bacteria, diet and stress have all been suggested as environmental triggers but there is no definite evidence that any one of these factors is responsible.

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 (especially in Crohn's Disease).

Sometimes the need to go to the toilet is so urgent that it can cause faecal incontinence (accidental leakage of faeces or stool).

Some children may also suffer from joint pains, eye problems, skin rashes, and mouth ulcers. IBD can also cause liver problems and anaemia.

WHAT CAN BE THE IMPACT OF HAVING IBD?

Delays in physical development

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

Effects of treatment

IBD usually requires life-long management and some treatments may have unpleasant side effects.

Drug treatment often includes using corticosteroids (steroids) to reduce inflammation. (These steroids are not the same as anabolic steroids sometimes used by athletes).

Unwanted side-effects of this type of drug, especially at high initial doses, can include:

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

Steroids can affect the adrenal glands if they are used for a long time. This reduces the body's ability to cope with stress, for example an operation or accident. A child on steroids may need to wear a steroid alert bracelet or carry a card.

Other drugs that may be given for IBD include anti-inflammatory drugs, immunosuppressants, and biologics or anti-TNF drugs (drugs which work with the immune system to block the chemicals which cause ongoing inflammation).

These may also have unwanted side effects such as

- headaches
- nausea or flu-like symptoms
- greater risk of infections due to a suppressed immune system
- greater sensitivity to sunlight (so sunblock will be needed for outdoor activities).

Children on these medications usually have to go to their doctor or IBD Clinic for regular blood tests and checkups. If they are on anti-TNF drugs such as infliximab or adalimumab, they may need to attend hospital on a regular basis for the drug infusion or injection.

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, sometimes months, at a time. Even 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 can be temporary but may be permanent. Some children with a temporary ileostomy may be able to have further surgery to create an internal 'pouch', and will no longer need a stoma bag.

Psychological effects

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

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, mealtimes can still be stressful and difficult 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.

“

When my son, Alex, has a flare-up, it not only affects him physically, but psychologically too as he is in pain and terrified of 'accidents'. This can make it very difficult to concentrate in the classroom.

”

Christine, mother to Alex, age 16
Diagnosed with Ulcerative Colitis in 2007

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 extracurricular activities.

It can be particularly 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 when they are feeling awful. This is especially likely if they are on steroids.

Teenagers with IBD may be at particular risk to themselves 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. This could mean that the stress of exams for example might trigger a relapse of symptoms.

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

IBD AND SCHOOL LEGISLATION

The most relevant pieces of legislation are, the:

- **Equality Act 2010** (which applies to England, Scotland and Wales)
- **Disability Discrimination Act 1995** (which applies to Northern Ireland only)
- **Children and Young People (Scotland) Act 2014**
- **Children and Families Act 2014** (which applies to England only).

The **Equality Act 2010** covers people with 'protected characteristics' such as people with disabilities. This may include children with IBD. 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 Act includes people with 'hidden impairments' such as incontinence which might hinder a person from continuing with their life as they usually would.

Under the Equality Act, a school has a duty to make 'reasonable adjustments' to make sure disabled students are not discriminated against. An example of a reasonable adjustment could be to allow a pupil access to toilets during lessons.

Up-to-date guidance on this and how it applies to schools is available from the Equality and Human Rights Commission website. (See **Further Information.**)

The Equality Act 2010 also introduced a single Public Sector Equality Duty (sometimes also referred to as the ‘general duty’) that applies to public bodies, including maintained schools, and covers all protected characteristics, including people with disabilities. Schools are required to publish information on how they are complying with this duty, and also prepare and publish objectives which further the aims of the Equality Duty. All schools in England, Scotland and Wales are also required to publish a Disability Equality Scheme to show how the school is meeting this duty.

The equivalent legislation in Northern Ireland is the **Disability Discrimination Act (DDA)**. Details on the DDA can be found on the Equality Commission for Northern Ireland 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 **Children and Families Act 2014** sets out in legislation how schools and academies (including alternative provision and Pupil Referral Units) will be expected to put in place appropriate support for pupils with medical conditions. Under the Act, educational opportunities and experience must be given equally to any pupil, whether or not they have a medical condition.

Consideration should be given to pupils who need:

- help with taking medication
- access to toilets nearby
- access to food and drink to manage their condition
- specific care to ensure their dietary needs are met
- extra time to complete exams, particularly if they have to visit the toilet frequently.

Schools will be required to train staff to provide the necessary support to fulfil the obligations of the Act.

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

The **Children and Young People (Scotland) Act 2014** and **Getting It Right For Every Child (GIRFEC)** cover a wide range of provisions, which look for ways to improve support services, including education, for children and young people in Scotland. More information can be found on the Scottish Government website at: www.gov.scot



HOW CAN SCHOOLS HELP?

- **Awareness and understanding**

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

Most children and young people with Crohn's 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 each pupil's particular needs with them and their parents, and possibly also with the 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.

- **Supporting the family**

Some parents may find it difficult to approach the school and may particularly benefit from teacher and school staff support. 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 might feel resentful of all the attention being given to 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.

If available, a SENCO (Special Educational Needs Coordinator) may be able to take on this role.

This designated person can discuss issues of concern with the pupil and their parents, 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 and care plan, for example when the child changes classes or moves from primary to secondary school.

“

I find keeping communication going with the staff is so important, whether it is at parents' evening or picking up in the playground, to make sure that they remember what Fergus needs.

”

Fiona, mother to Fergus, age 11
Diagnosed with Crohn's Disease in 2010



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 can 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. To make this easier the child could perhaps use a 'secret signal' when they need to go to the toilet, or show a 'Can't wait card' such as that supplied by Crohn's and Colitis UK. 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 or disabled 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 must 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 a pupil can carry and take their own medication should involve the young person and their parents, together with their health professionals if appropriate.

- **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 they have been affected by pain or needing to go to the toilet during the meal. Their doctor or dietician may advise eating small amounts regularly from a wide range of foods in order to ensure that they eat enough food to meet their needs. Their diet may also be supplemented by proprietary liquid meals. All this may mean pupils with IBD will need extra or longer 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 so, it may be helpful if the child could have access to a fridge in which to store the liquid diet.

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.

“

Alex was given a toilet pass and was allowed to leave lessons when he needed to, which was a great help.

”

Christine, mother to Alex, age 16
Diagnosed with Ulcerative Colitis in 2007

66

When my daughter, Emma, had a flare-up, the school let her use the disabled lift, and sometimes allowed her to leave early, because she was so exhausted.

99

Helen, mother to Emma, 19,
diagnosed with IBDU in 2005

66

The school were very good at notifying us of infection, particularly chickenpox and stomach bugs.

99

Christine, mother to Alex, age 16
Diagnosed with Ulcerative Colitis in 2007

- **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.

- **Infection**

If a child is on immunosuppressants, biologics, or steroid medication, their ability to fight infection will be reduced. This means that some infectious illnesses, such as chicken pox or measles can be very serious. It may be useful to ensure that the child or their parents are aware of any infectious diseases going through the school.

- **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 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 work load.

- **PE and sport**

Strenuous physical exercise can trigger an urgent need to go to the toilet, or joint pains. Even mild exertion 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 on a day-to-day basis but also to treat them the same as other pupils as far as 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. The Education Act 1996 requires that arrangements are made for children who due to illness would not otherwise receive suitable education. Children should not be home unwell for more than three weeks without some suitable form of tuition.

If a pupil is resting 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 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. Encouraging classmates to stay in touch by phone or email, or by sending cards, can help them feel less isolated.

66

My daughter was able to go on every school trip, even a residential one in Spain. Though I always provided the school with written guidance about what to do if she became unwell.

”

Helen, mother to Emma, age 19
Diagnosed with IBDU in 2005

- **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 pupils may also need extra time if they have to take extra toilet 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.

- **School Trips**

Outings can be very stressful 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.

IBD can be very unpredictable, so it may be helpful, if possible, to have arrangements in place for a pupil to 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.

- **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.

One useful approach to help counteract this might be to provide information about IBD to a small group or the whole class during a PSHE or citizenship lesson. A health professional such as an IBD nurse may be able to assist with this. General information about IBD is also available on the Crohn's and Colitis UK website and from our office. 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 a counsellor.

Some children and young people will have a specialist IBD nurse as part of their hospital team who may be willing to come into the school and discuss ways to help support young people with IBD.

FURTHER INFORMATION

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.

Disability Discrimination Act 1995 (Northern Ireland). Information relating to this Act can be found on the Equality Commission for Northern Ireland website: www.equalityni.org

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.

Supporting pupils at school with medical conditions (2014). This is statutory guidance about the support that pupils with medical conditions should receive at school. To find out more about this, see the government website at: www.gov.uk

Children and Families Act (2014). This is legislation which outlines new protections in law to:

- help vulnerable children
- offer new support for children whose parents are separating
- provide a new system to help children with special educational needs and disabilities
- assist parents to balance work and family life.

The full details on the Act can be found on the government legislation website: www.legislation.gov.uk

There is also information about the Act written for young people. For further details about this, visit www.gov.uk

OTHER USEFUL ORGANISATIONS

Crohn's in Childhood Research Association (CICRA)

Telephone: 020 8949 6209.

Website: www.cicra.org

Email: support@cicra.org

Health Conditions in Schools Alliance

Website: medicalconditionsatschool.org.uk

The Alliance website offers tools and guidance to schools.

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

Telephone: 0800 018 4724

Website: www.iasupport.org

Email: info@iasupport.org

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

Website: www.pinnt.com

ERIC (Education and Resources for improving Child Continence)

Website: www.eric.org.uk

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

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.

Contact a Family

Website: www.cafamily.org.uk

Helpline: 0808 808 3555

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

IPSEA (Independent Parental Special Education Advice)

Website: www.ipsea.org.uk

Telephone: 0800 018 4016

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

SUPPORT SERVICES PROVIDED BY CROHN'S AND COLITIS UK

All our information sheets and booklets are available free from our office and downloadable from our website: www.crohnsandcolitis.org.uk

Crohn's and Colitis UK Information Line: 0300 222 5700, open Monday to Friday, 9 am to 5 pm, except Thursday open 9 am to 1 pm, and excluding English bank holidays. An answer phone and call back service operates outside these hours. You can also contact the service by email info@crohnsandcolitis.org.uk or letter (addressed to our St Albans office). Trained Information Officers provide callers with clear and balanced information on a wide range of issues relating to IBD.

Crohn's and Colitis Support: 0121 737 9931, open Monday to Friday, 1 pm to 3.30 pm and 6.30 pm to 9 pm, excluding English bank holidays. This is a confidential, supportive listening service, which is provided by trained volunteers and is available to anyone affected by IBD. These volunteers are skilled in providing emotional support to anyone who needs a safe place to talk about living with IBD.

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 and can be contacted through the Information Line.

The Family Network is a UK wide network which offers support for children with IBD and their families, and arranges Fun Days for the families and children to meet. It can be contacted via the Crohn's and Colitis UK website.

The Disability Benefits Service is a confidential service run by trained volunteers to provide support and information to people with IBD who are applying for DLA or Personal Independence Payment (PIP). Appointments can be arranged by phoning the Information Line.

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. We also offer small Educational and Vocational Grants for young people with IBD between the ages of 15 and 25. See our website for more details.

.....

© Crohn's and Colitis UK 2013, 2014, 2015 and 2016
Children and Young People: a guide for schools Edition 6b – Amended February 2016
Last full review October 2013
Contact details updated October 2015
Next planned review 2016

.....

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

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 (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 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 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 teachers and other pupils are told.
- Try to be alert for bullying from others.
- 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, 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, 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.
- Arrange a liaison teacher for the child/young person, their parents and other teachers to talk to.
- For more details, contact the Crohn's and Colitis UK Information Line on 0300 222 5700, email info@crohnsandcolitis.org.uk or visit www.crohnsandcolitis.org.uk

Follow us

 /crohnsandcolitisuk

 @CrohnsColitisUK



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 and the Information Standard website: 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. You can also write to us at Crohn's and Colitis UK, 45 Grosvenor Road, St Albans, AL1 3AW or contact us through the Information Line: 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 28,000 members and 50 Local groups 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

