IBD and secondary schools

information for form teachers, year heads, pastoral staff, attendance and examinations officers

cicra

better lives for children with crohns and colitis

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

images by Vicki Sharp Photography

what is IBD?

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

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

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 Combined with the strain of living with their condition, this can make them become withdrawn, **anxious and depressed.** Relapses can be particularly difficult to **deal with emotionally.**

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

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

what are schools' responsibilities?

Staff in schools are generally keen to support children and young people with health needs and can refer to guidance from government education departments to help them do this. The guidance clearly sets out a school's responsibility for supporting pupils with medical needs.

Schools should have a written policy on supporting children's medical needs. This should include:

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

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

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

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

how can the school help?

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

access to toilets

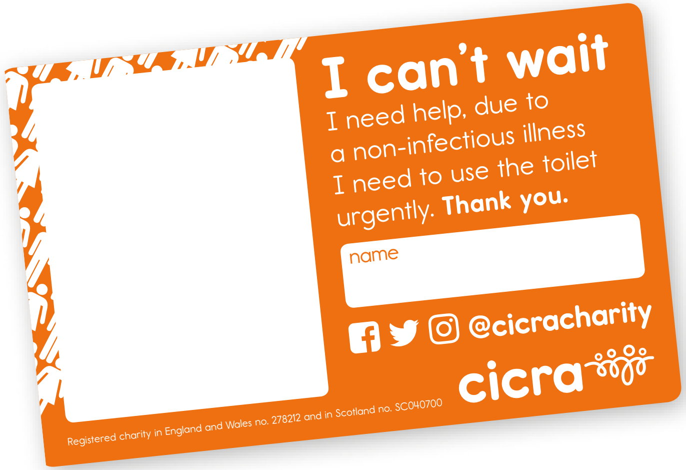
Children with IBD need access to clean toilets, with lockable doors that provide as much privacy as possible. Children need free access to toilets throughout the day.

If toilet facilities for pupils do not meet these criteria then consideration should be given to letting children with IBD use staff facilities. Children should also have somewhere to wash if necessary and store clean clothes.

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

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

"My greatest problem is being able to get to a toilet in time."



I can't wait

I need help, due to
a non-infectious illness
I need to use the toilet
urgently. **Thank you.**

name

@cicracharity

cicra

Registered charity in England and Wales no. 278212 and in Scotland no. SC040700

secondary school

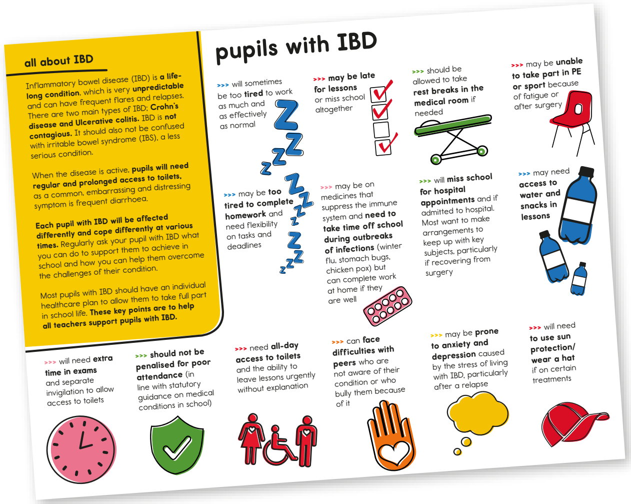
Coping with secondary school for children with IBD is a challenge. Most children will have between 12 and 16 teachers and move around the school for different subjects. Urgent access to clean and private toilets is the most pressing concern for children, so it is important for all a child's teachers to be aware of their IBD and understand the impact this can have on their attitude and behaviour in school.

Children may arrive at secondary school with a diagnosis and their needs can be considered as part of the transfer from primary school, or they may become ill and get a diagnosis while at secondary school. Diagnosis of a life-changing and life-long condition has a significant emotional impact. Most people will go through a grief cycle of denial, anger and depression before reaching acceptance, and young people are no exception.

It is important that subject teachers are aware of the physical and emotional impact of IBD. The key points for subject teachers are set out in a single-page summary leaflet, available from CICRA.

Copies of this leaflet are available from CICRA's website: cicra.org. Many children will also carry a Can't Wait card and teachers should be made aware of the Can't Wait scheme and allow children who have a card to leave the class without further explanation.

> **"My form teacher has helped me organise a sponsored swim for CICRA in our school pool and my form are being really supportive. It has helped me talk about my IBD."**



all about IBD

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

When the disease is active, **pupils will need regular and prolonged access to toilets,** as a common, embarrassing and distressing symptom is frequent diarrhoea.

Each pupil with IBD will be affected differently and cope differently at various times. Regularly ask your pupil with IBD what you can do to support them to achieve in school and how you can help them overcome the challenges of their condition.

Most pupils with IBD should have an individual healthcare plan to allow them to take full part in school life. **These key points are to help all teachers support pupils with IBD.**

pupils with IBD

>>> will sometimes be too **tired** to work as much and as effectively as normal

>>> **may be late for lessons** or miss school altogether

>>> should be allowed to take **rest breaks in the medical room** if needed

>>> may be **unable to take part in PE or sport** because of fatigue or after surgery

>>> may be **too tired to complete homework** and need flexibility on tasks and deadlines

>>> may be on medicines that suppress the immune system and **need to take time off school during outbreaks of infections** (winter flu, stomach bugs, chicken pox) but can complete work at home if they are well

>>> will **miss school for hospital appointments** and if admitted to hospital. Most want to make arrangements to keep up with key subjects, particularly if recovering from surgery

>>> may need **access to water and snacks in lessons**

>>> will need **extra time in exams** and separate invigilation to allow access to toilets

>>> **should not be penalised for poor attendance** (in line with statutory guidance on medical conditions in school)

>>> need **all-day access to toilets** and the ability to leave lessons urgently without explanation

>>> can **face difficulties with peers** who are not aware of their condition or who bully them because of it

>>> may be **prone to anxiety and depression** caused by the stress of living with IBD, particularly after a relapse

>>> will need **to use sun protection/ wear a hat** if on certain treatments

medications and side effects

During the school day, the school has a duty to take sole care of a young person and their medical needs and to administer medication. Some children will be competent to manage their medication; if so, this will be set out in their healthcare plan.

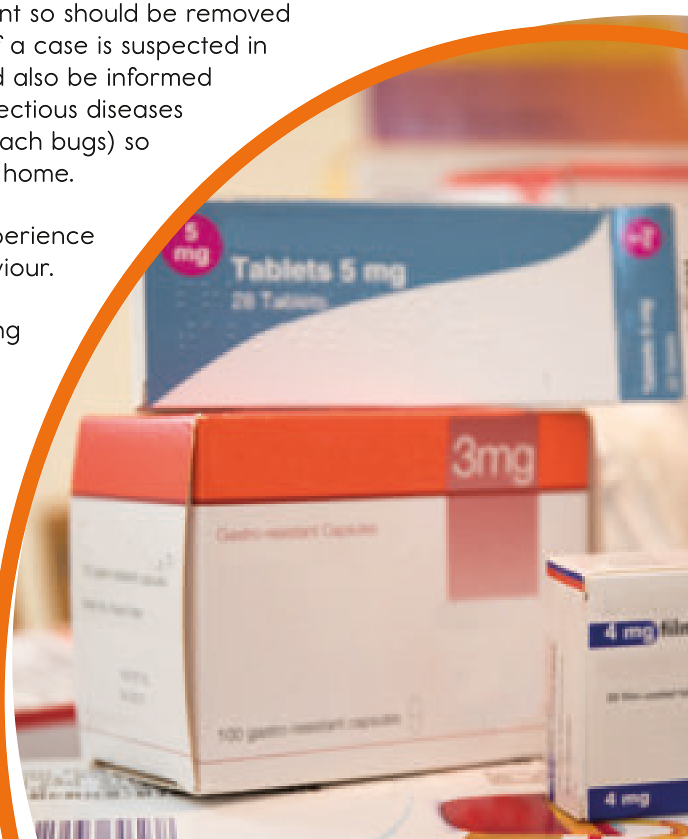
Some pupils have a liquid nutritional feed, which needs to be kept refrigerated. Children should be able to have their feed with their peers at lunchtime.

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

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

Children on steroids can experience changes in mood and behaviour.

New treatments are emerging for IBD, so schools should ask parents about their child's treatment and any side effects that may need to be taken into consideration. If a pupil has a healthcare plan, this can be included in the annual review.



inclusion

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

Schools cannot exclude children from school trips on the basis of medical conditions, nor can they require parents to accompany them. Children should be allowed to participate fully in out-of-school activities, if they feel well enough, and their specific needs should be considered as part of the normal risk assessment for school trips.

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

attendance

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

Schools rightly place importance on attendance. However, some schools' attendance policies penalise poor attendance and this can be devastating to pupils with medical conditions who have really tried to be in school despite the challenges of their disease. Examples include being denied study leave for exams or access to very special events like the Year 11 leavers' prom. The statutory guidance makes clear these types of policies are unacceptable and discriminate against children with health conditions.

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

When absences are under 15 days, many children still want to keep up with key subjects, particularly if they are well and at home during an outbreak of infectious disease. Providing children with some work to do at home helps them keep up with the rest of the class. Sending work by email via parents allows the school, child and parent to work out what can be managed.

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

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

> **“I was told I couldn't go to prom because my attendance wasn't good enough even though I'd had major surgery.”**

friendships and bullying

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

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

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

> **"If I had my arm in a plaster people could understand."**

consider a reduced timetable

Adjustments will depend on the severity of a pupil's IBD, but might include a reduced timetable, dropping some exam subjects and avoiding PE. These types of adjustments result in a reduction in stress and an improvement in attendance.

SATS and tests

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

Visit our website cicra.org for downloadable template letters to exam boards.

GSCEs, Nationals and other formal examinations

Children with IBD will need special arrangements for external examinations. It is recommended that schools meet with parents to discuss arrangements to support children with IBD at the point at which options are chosen. Stress does not cause IBD, but it can make the disease more active.

> **"I took two out of the four GCSE French papers by arrangement with the exam board because I had been so ill. It made a real difference to me and I passed!"**

separate invigilation and extra time

Examinations officers should be notified of a child's condition to allow for deadline extensions or 'shortfall of work' arrangements for coursework.

During exams, children with IBD may be disadvantaged by:

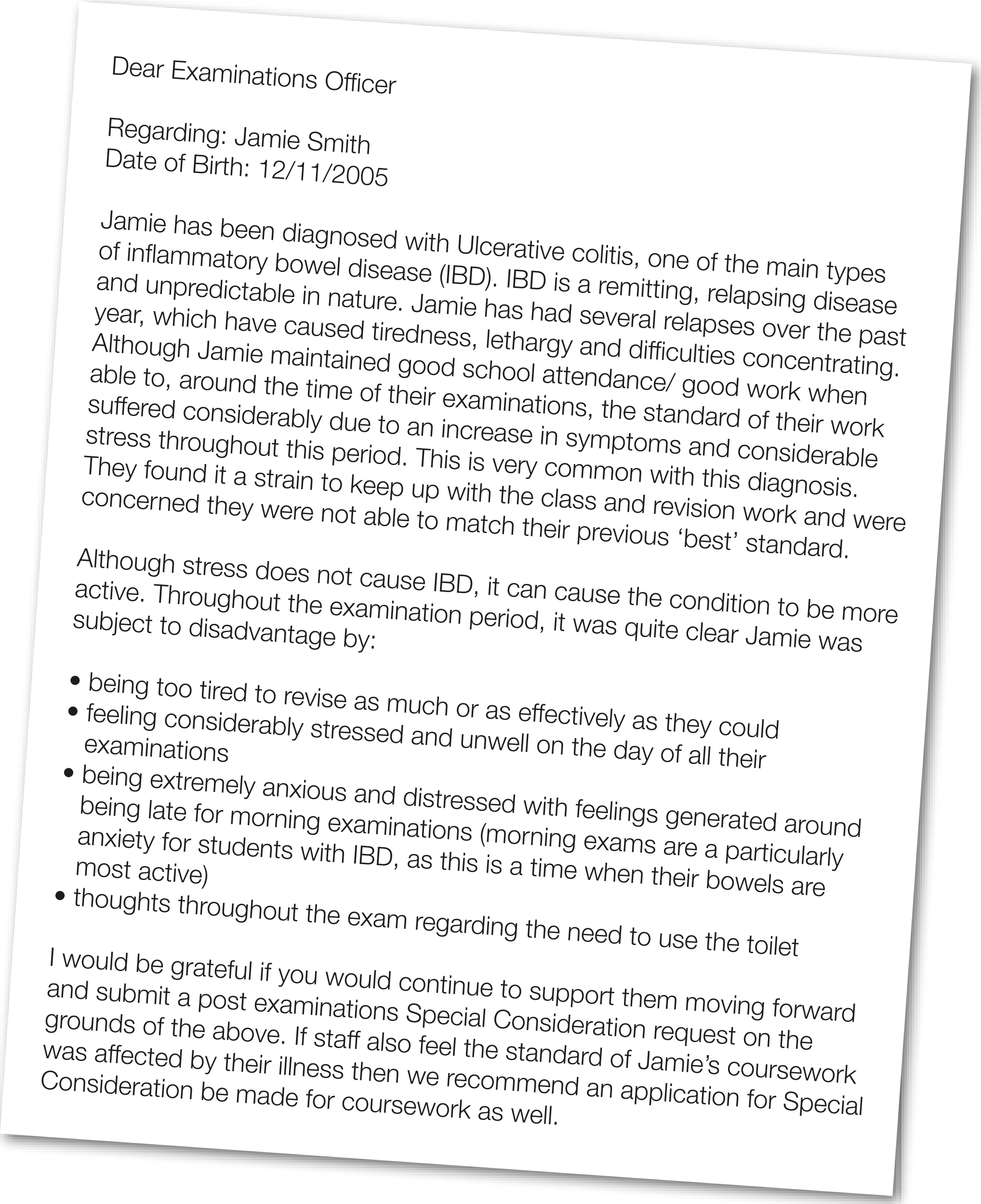
- being too tired to revise as much or effectively as they could
- feeling considerably stressed and unwell on the days of examinations
- being extremely anxious with concerns about being late for morning exams (bowels are normally most active in the morning)
- thoughts during the exam about needing to use the toilet

It is normally recommended that children with IBD have separate invigilation so they can have free access to toilets during examinations and have 25% extra time. If a student has been very unwell, hospitalised or had surgery, the exam board should be asked to give them special consideration.

A student's medical team will provide a supporting statement describing a child's symptoms, side effects and the impact on their learning. An example can be found at the back of this booklet.

transfer to college

Transferring to college is an exciting but also daunting prospect. Encourage children to ask about support for health conditions when they visit colleges.



Dear Examinations Officer

Regarding: Jamie Smith
Date of Birth: 12/11/2005

Jamie has been diagnosed with Ulcerative colitis, one of the main types of inflammatory bowel disease (IBD). IBD is a remitting, relapsing disease and unpredictable in nature. Jamie has had several relapses over the past year, which have caused tiredness, lethargy and difficulties concentrating. Although Jamie maintained good school attendance/ good work when able to, around the time of their examinations, the standard of their work suffered considerably due to an increase in symptoms and considerable stress throughout this period. This is very common with this diagnosis. They found it a strain to keep up with the class and revision work and were concerned they were not able to match their previous 'best' standard.

Although stress does not cause IBD, it can cause the condition to be more active. Throughout the examination period, it was quite clear Jamie was subject to disadvantage by:

- being too tired to revise as much or as effectively as they could
- feeling considerably stressed and unwell on the day of all their examinations
- being extremely anxious and distressed with feelings generated around being late for morning examinations (morning exams are a particularly anxiety for students with IBD, as this is a time when their bowels are most active)
- thoughts throughout the exam regarding the need to use the toilet

I would be grateful if you would continue to support them moving forward and submit a post examinations Special Consideration request on the grounds of the above. If staff also feel the standard of Jamie's coursework was affected by their illness then we recommend an application for Special Consideration be made for coursework as well.

Sources:

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

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

support@cicra.org

0208 949 6209

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

cicra.org

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

@cicracharity

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better lives for children with crohns and colitis

Crohn's in Childhood Research Association
Pat Shaw House, 13-19 Ventnor Road, Sutton, Surrey SM2 6AQ
Registered charity in England and Wales no. 278212 and in Scotland no. SC040700