

For help and guidance:

Call: 020 8949 6209

Email:

support@cicra.org



guide to school for parents and carers

- what should be in place for your child with IBD?
- individual healthcare plans / school support
- explaining IBD / fatigue
- planning for exams

School – what should be in place for your child with IBD?

At CICRA, we know from the contact we have with families that school may be a difficult place for some young people with IBD if they are not fully supported and their illness not properly understood. We hope that the information in this booklet will be of help regardless of what stage of education your child is at. The most important thing is to contact your school, preferably making an appointment with the SENCO (the person appointed by the school to support children with special educational needs including those who could be hindered by health problems) to ensure they are aware of the problems that any form of Inflammatory Bowel Disease (IBD) can cause.

We appreciate that there is a lot of information to take on board and it can be difficult navigating it all. But we are here to help, and we have lots of useful resources proven to work and ensure your child can achieve their potential.

In this leaflet are links to many useful websites outside of CICRA. If you are looking at the printed copy you can access this information by copying the full link into a browser/web address bar.

To download any of the CICRA information or leaflets, copy the following link into a browser: <https://www.cicra.org/how-we-can-help/schools-and-colleges/> Hard copies of the CICRA information can be obtained by emailing support@cicra.org or calling 020 8949 6209.

Please do not hesitate to contact us if there is anything you would like to talk through about your child's IBD or the effect this is having on their schooling.

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Special Educational Needs (SEN)

A child with a long-term health condition is considered to have special educational needs (SEN) and as such, should have involvement from the school special educational needs coordinator (SENCO) to ensure that their holistic needs are understood and supported. The link below takes you to the SEN code of practice for each nation:

England: <https://www.gov.uk/government/publications/send-code-of-practice-0-to-25>

Northern Ireland: <https://www.eani.org.uk/parents/special-educational-needs-sen>

Scotland: <https://www.gov.scot/publications/supporting-children-young-people-healthcare-needs-schools/>

Wales: <https://gov.wales/special-educational-needs-code-practice>

Some schools have been resistant to accepting that a child with IBD has a special educational need, often because the condition is not a 'learning disability'. However, they are entitled to this support and school need to understand that your child may not be able to attain a full attendance record due to their illness, hospital appointments etc. and the impact that this may have on their work, exams etc. We would advise that you request, as soon as possible, a meeting with the school to discuss your child's illness and his/her needs, taking with you the following:

- a letter from your child's consultant/nurse specialist explaining what IBD is and what it means for your child. An example of a letter is available on the CICRA website:
<https://www.cicra.org/media/1758/example-health-professional-letters-to-schools-for-pupils-with-ibd.docx>
- Information from CICRA as appropriate
 - [guide for primary schools](#)
 - [guide for secondary schools](#)
 - [guide for class teachers](#)
- a list of things that you would like included in an Individual Healthcare Plan (IHP) and ask the SENCO to complete this for you. Once in place this should be reviewed on an annual basis and updated if things change with your child's needs/treatment plan. Getting this in place sooner rather than later can help prevent issues from arising later and perhaps becoming problematic.

(Hard copies of the letter and guides are available by emailing support@cicra.org or calling 020 8949 6209)

Individual Healthcare Plans (IHPs) / School Support

All children with IBD should have an Individual Healthcare Plan (IHP) in place at school regardless of their IBD status. Whether in remission or actively flaring, an IHP is important. An IHP is not to be confused with an Educational Healthcare Plan (EHCP) which is a more formal process that we will explain further on. Essentially an IHP is a way of drawing up a plan between yourself (including your child where appropriate) and the school, ensuring that your child's needs are understood and well supported. Its purpose is also to ensure effective, consistent communication both with you and your child, but also internally amongst relevant staff, hopefully avoiding the need for you to keep explaining!

The three links below provide information and a proposed template for completing an IHP, it doesn't have to be recorded in this way, your school may have their own template, or you may just want to type it up in a word document, but however you do it, ensure that you have a copy in writing that is signed (by school and yourself) and dated. The template provided, does have a focus on administering medication which may not be relevant to your child and may not be the key reason for wanting an IHP. In our experience, most parents require an IHP to aid the school's understanding of IBD particularly as this is a hidden illness, varies considerably between those affected and there is no way of knowing when a 'flare' may occur or preventing this happening.

[Guide to Individual Healthcare Plans](http://www.medicalconditionsatschool.org.uk/documents/individual-healthcare-plan-part-1.pdf)

<http://www.medicalconditionsatschool.org.uk/documents/individual-healthcare-plan-part-1.pdf>

[Template Individual Healthcare Plan](http://www.medicalconditionsatschool.org.uk/documents/individual-healthcare-plan-part-2.pdf)

<http://www.medicalconditionsatschool.org.uk/documents/individual-healthcare-plan-part-2.pdf>

[Government guidance on supporting pupils at school with a medical condition](https://www.gov.uk/government/publications/supporting-pupils-at-school-with-medical-conditions-3)

<https://www.gov.uk/government/publications/supporting-pupils-at-school-with-medical-conditions-3>

In terms of what you may want to include in the IHP, we would encourage you to consider both practical and emotional needs.

Practical Arrangements

The list below is not exhaustive, and you will know what specific considerations need to be included for your child, but the school needs to be aware of, and accommodate, the following:

- ease of access to toilets
- support he/she may need with personal care (either with using the toilet or accessing/changing clothes discreetly if necessary)
- places he/she can go for rest breaks if needed
- ways for he/she to communicate their needs and how they are feeling

It is important that all key information is written into this plan relevant to your child and that the school understand the fluctuating, flaring nature of IBD and how stress can exacerbate symptoms. It is therefore important that your child feels comfortable and able to communicate their needs, knowing that they will be listened too and acted upon.

For some children with IBD, getting to a toilet is a constant worry. CICRA members are issued with a 'Can't Wait' card and Radar key (necessary when using a toilet for the disabled). Most schools accept the Can't Wait card as proof to school staff that your child is allowed to visit the toilet without questioning.

Emotional Impact of IBD

Children with IBD can often be quite resilient but there is no denying the emotional impact that a diagnosis of IBD may have on their day-to-day life. Coupled with the fact that many children do not want to be singled out as being different or be seen to have 'special treatment' at school, they can become experts in 'covering up' how they are feeling (whether this is playing down IBD symptoms or the emotional toll it is having on them). As a parent/carer you may intuitively pick up on signs and subtle changes in your child that could indicate there is something wrong. You may also be familiar with signs that your child's IBD is beginning to flare. These things are less likely to be picked up at school and as such, the IHP should take this into account so that relevant staff are aware and look out for behavioural changes. Fatigue is a part of having IBD and if your child is affected by this, we would suggest including it within the IHP. The impact of fatigue can be debilitating at times, and it is important that school understands (see below for detailed information)

Named Teacher/Pastoral Worker

We would suggest having a named teacher/pastoral worker who schedules some 1:1 time with your child each week as a way of 'checking in' and making sure they are feeling ok and managing the workload without feeling under too much pressure. This 'check in' does not need to be anything lengthy, perhaps just 5-10mins at an agreed time, before or after break/lunchtime. We appreciate that this may not be welcome by some, particularly those at High School. Where this is the case, we would suggest having a named teacher that your child knows to approach, when necessary, alongside an agreed plan that will enable your child to seek out this support discreetly.

We would also encourage regularly scheduled telephone calls between school and yourself (same teacher/SENCO each time) just to ensure that both you and they are keeping one another up to date and can pass on any relevant information or concerns. Again, this does not need to be anything lengthy, it is not resource intensive but could make a huge difference to everybody's experience, most importantly your child's.

Explaining IBD and Fatigue to School

In terms of discussions with school, both generally and when drawing up the IHP, it is important that the SENCO and other staff understand what IBD is and that they are not confusing it with IBS (a much less serious condition). Most importantly, IBD can affect children very differently, depending on which part of the digestive tract/intestine is affected. As well as the various information/resources you can access through CICRA, the information below may provide a useful read, it is aimed at schools and suggests ways of offering support and understanding to pupils with these diagnoses.

[Well at School guide to inflammatory bowel disease](https://www.wellatschool.org/inflammatory-bowel-disease)

<https://www.wellatschool.org/inflammatory-bowel-disease>

[Well at School guide to chronic fatigue syndrome](https://www.wellatschool.org/chronic-fatigue-syndrome)

<https://www.wellatschool.org/chronic-fatigue-syndrome>

Evie's story is a great example of how schools can work alongside families and support children with IBD.

[FINAL Evie's story going to school with medical needs.pdf \(leeds.gov.uk\)](#)

Educational Healthcare Plans (EHCPs)

In the majority of cases, where schools have an effective IHP in place (which is regularly reviewed) and they are supporting a child who is feeling mostly positive and achieving their goals, an IHP should be sufficient. However, if there are occasions where an IHP is not achieving what it should for the young person, it is important in this case to address this with the school. It may be that an Educational Healthcare Plan (EHCP or EHP, depending on the locality – they are the same thing) is needed. An EHCP is a more formal process and one that you must apply to your local authority for. Once an application/referral has been made, the local authority will decide, based upon the information provided, whether they will independently assess your child's needs to determine whether an EHCP is required. It is very unlikely that a local authority will agree to conduct an assessment without evidence that an agreed support plan between you and school already exists. This is another reason why it is useful to have an IHP in place, because if things are not working, you have the evidence already available to prove to the local authority that discussions have happened, and a plan has been implemented. If no discussions/plans with school have taken place, the local authority are likely to recommend that this is the first thing that must be done, as in many situations, the school can meet the needs of children with special educational needs with their own resources and access to services.

The IHP provides evidence that communication has taken place between yourselves and school in relation to your child's health and wellbeing needs, and how school have agreed to support your child. Once an IHP is in place there are 2 specific reasons why you may feel an EHCP is needed:

1. If the plan is being adhered to, all available resources are being utilised/access arrangements have been put in place by school, but it is felt that the child still isn't receiving enough support, school or you could apply for an EHCP.
2. If as a parent/carer, you feel that school are not consistently adhering to the plan or following through with what they agreed you can apply for an EHCP.

NB: It is always preferable to have school on board when applying for an EHCP, but you can apply as a parent, without involving the school, if this is proving to be a stumbling block for you. If the local authority agrees to assess, the school will have to co-operate.

Outcome of an Assessment

If the local authority agrees to assess your child, you will be involved in the process, as will school, and any other services that your child may access i.e., out of school clubs. This allows the Assessor to look holistically at your child's needs and how they are supported outside of the school environment, to see whether things that are working well in other aspects of their life can be mirrored at school in some way. It is important to note that the assessment itself does not automatically result in an EHCP, if there are some relatively 'easy' things that can be implemented at school this will be documented as part of the assessment and a recommendation made to school. If the assessment reveals that things are more complex and additional support/services need to be implemented that are outside the realm of what school can ordinarily access, an EHCP may be deemed necessary. If an EHCP is put in place, this is a legal document and school have a duty to support your child in line with this plan. It must be reviewed annually as a minimum or when things change (i.e., new school/year group or changes to your child's health). An EHCP can stay with your child up to the age of 25 and could help with getting a priority school place, if for example you feel that there is a high school that will best meet your child's needs but isn't your catchment school.

EHCP information

England: <https://www.gov.uk/children-with-special-educational-needs/extra-SEN-help>

Northern Ireland, Wales and Scotland have slightly different processes/names but they do have an equivalent <https://contact.org.uk/advice-and-support/education-learning/education-in-northern-ireland-scotland-wales/>

All localities differ slightly in terms of how they assess and carry out EHCPs, if you search 'Educational Healthcare Plan' or 'special educational needs support in school' followed by the geographical area that you live in, you should be directed to the most relevant information for your locality.

Impartial Advice and Local Knowledge

Various services operate across the UK offering free impartial, confidential, information, advice and support about education, health and social care relating to special educational needs and disability. They are normally a very good source of information, not least because they have knowledge about how your local authority operates and are familiar with other local services that may be available to you.

England: SENDIASS (Special Educational Needs and Disabilities Information Advice and Support Service) operates in many places across England.

Wales: <https://www.snapcymru.org/about-us/>

Scotland: <https://enquire.org.uk/>

Northern Ireland: <http://www.senac.co.uk/>

Planning for Exams

The reason we suggest having an IHP in place for every child with IBD, even if they are stable/in remission, is because of the unpredictable, flaring nature of the illness. Your child may go through the whole of their school life without school being aware of their diagnosis because it is so well controlled and impacts minimally on their life, if so, that is brilliant. However, there have been situations where a young person has gone through the first 3 years of High School in this way, only to have a flare up in their 4th or 5th year just as they are focussing on GCSEs. Stress can for some children cause their IBD to be more active, therefore it is good to plan with the school to consider the possible impact that exam pressures may have on your child. It is good to have these conversations as early as possible because whilst there are things that can be put in place relatively easily to support your child, there are other elements that may need to be applied for, with supporting evidence to prove the need. If the school have not been informed of the pre-existing diagnosis of IBD until this point, it can make the process of applying for access arrangements etc more complicated for them and subsequently more stressful for you as a family, than if they had been told previously and preparatory conversations had taken place about what action to take if things do flare.

Our leaflet '[Access Arrangements and Special Consideration](#)' put together by Steve Green (Deputy Head at the Royal Free Hospital School) provides a snapshot of all the things that can be done ahead of exams, or where necessary, after exams have been taken. Several things can be implemented internally i.e., for exams, positioning close to an exit so that your child can take rest or toilet breaks as and when needed. Copies of this leaflet can be obtained by contacting support@cicra.org or calling the office on 020 8949 6209.

However, if extra time for exams is to be applied for, this needs to be considered well in advance, so as to be able to produce enough supporting evidence to the JCQ (Joint Council for Qualifications) as to why your child is eligible. It must be proven that this forms part of your child's 'normal way of working'.

For example, school would need to prove that on a day-to-day basis, extra time is needed for your child to complete work. This may be associated with chronic fatigue, a symptom associated to their IBD, which has resulted in their ability to process information being slower than it would otherwise have been if they didn't have IBD” This kind of statement often needs to be backed up by assessments and observations that the school will need to arrange, hence the need for as much time as possible so as to be able to build a picture and put forward supporting evidence. (See document [checklist normal way of working: https://www.cicra.org/media/2363/checklist-normal-way-of-working.pdf](https://www.cicra.org/media/2363/checklist-normal-way-of-working.pdf))

NB: The deadline for applying to the JCQ for extra time is at least 4 months before exams are due to begin.

We appreciate that there is a lot of information to take on board and it can be difficult navigating it all. Please do not hesitate to contact us if you want to talk this through in the context of your situation. We will do all we can to help guide you through various stages to get the support your child needs at school.



We are the specialist charity for children and young people affected by Crohn's and Colitis.

We **lead research** into better treatments, **support children and families** with relevant information, work with health professionals to **improve care** and **give children a voice** to increase public understanding of Crohn's and Colitis.

We believe that all children deserve a childhood unlimited by inflammatory bowel disease

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CICRA is the operating name of Crohn's In Childhood Research Association, a registered charity in England and Wales (Number 278212) and Scotland (SC040700)