Do you work with children or young people?

Here's how you can give the right support to those who have Crohn's or Colitis

Children and young people with Crohn's or Colitis face very particular challenges during their education. This leaflet is designed to help you give them the support they need in managing their condition and treatment, so they get the most out of their time at school, college, university or other education environment.

What are Crohn's and Colitis?



- Crohn's or Colitis often referred to as Inflammatory Bowel Disease (IBD) affects children and young people in different ways. It's not contagious, but it is a long-term condition and at present there's no cure.
- Typically, Crohn's or Colitis causes bad abdominal pains, diarrhoea, fatigue, weight loss, nausea and anaemia (not having enough red blood cells). People with IBD tend to feel generally unwell. It can also affect other parts of the body sometimes people get arthritis, mouth ulcers, skin rashes, and sore, red eyes.
- It's usually treated with a medicine, and sometimes through a special diet too. Children and young people will have frequent hospital check-ups and may occasionally need to stay in hospital for treatment.

+ Crohn's and Colitis are not the same as IBS (Irritable Bowel Syndrome).

How might Crohn's or Colitis affect their experience at school?

- School life can be difficult: children and young people may struggle to attend or keep up in classes. They may be absent a lot through being unwell, or because they have frequent clinic visits or time in hospital. This means missing out on their education as well as time with friends, joining in social activities and making connections.
- They can be embarrassed and worried about their condition. They may dread having to rush for the toilet, be worried about having an 'accident', or fear being ridiculed.
- * Some young people may not want close friends or teachers to know, and could be worried about people finding out.
- They might find it hard to explain what it's like to have IBD or how they are feeling.
- Some children and young people with IBD can feel different to their peers. This may make it harder to make friends and grow friendships.
- Some children and young people can feel isolated, anxious, lonely, and/or depressed. Sadly, they can be teased or bullied about their IBD.

How might Crohn's or Colitis impact their education?

Crohn's or Colitis affects everyone differently. Most children and young people continue to attend school, take part in sports and other social activities, and do as well as their peers.

Edge Hill

University

MANCHESTER

The University of Manchester

- Some of the medication they have to take can cause unpleasant side effects, such as weight gain, mood swings, headaches, nausea, and being susceptible to infection.
- Some children and young people need to have a special diet. For some, this diet is delivered via a fine tube passed through their nose down into their stomach, this tube can make them feel self-conscious.
- They may worry about not doing well if they miss a lot of lessons or lectures and may struggle to catch up with work.

WHAT WILL THEY THINK ABOUT MY CROHN'S?

How you can help?

There's lots you can do to help them with their education and the experience they have getting it.

- Be sensitive to their needs and respect their wishes.
- Offering support can make a real difference and help young people to be part of your school, college or university community. This helps them feel better and achieve more academically and socially.
- Each person will have their own view about how they want to be treated and what support they would like. Some will want to keep their condition private, others may not mind their friends and other people knowing.
- Having someone they know they can talk to at school, college or university can be helpful.
 - You may want to explore together how they can be supported with:
 - Practical arrangements. For example, being able to sit close to exits, using a locker for spare clothes, permission to use staff toilets, a private room to use, and breaks to take medication.
 - Help coping with stress.
 Stress can impact IBD, so they may appreciate extra support during stressful periods.

- Needing to go to the toilet. Sometimes, they may need to go to the toilet frequently during the day and they may spend a long time there. They may prefer to use the disabled toilet because it is more private for them. They may also appreciate a discrete way of telling teaching staff that they need to go to the toilet.
- Attendance or lateness. They may need extra flexibility if they are late or miss teaching sessions due to medical appointments, hospital admissions or illness, or needing to go to the toilet.
- Pain and exhaustion. Both pain and exhaustion can affect concentration in class, so having time and a place to rest may help them stay on top of their studies.
- Educating their peers about IBD. This must be done in negotiation with the young person, but helping their peers understand more about IBD could help with friendships and understanding.
- Extra-curricular activities. Young people with IBD may feel less able to join in clubs and activities. Encouragement or adjustment may help them to stay involved with these activities and feel connected to these aspects of the school or college community.

Two BIG things you can do to help:

Develop a plan – create a plan in partnership with the young person (and their parent or carer, as appropriate) which ensures their needs can be met during all classes and activities.

Provide additional training for staff – help their teachers/lecturers develop their knowledge, understanding and sensitivity of chronic health conditions and the ways it affects their teaching.

Want to find out more about Crohn's or Colitis?

- Based on our research we have created an animation called 'Telling My Friends' along with some related information sheets. https://ehu.ac.uk/crohnsorcolitis
- There is a great animation about the condition on the Crohn's and Colitis UK website: www.crohnsandcolitis.org.uk/about-crohns-and-colitis
- You can also use the immersive In My Shoes app; this app will allow you to experience first-hand what it's like to have Crohn's or Colitis.
 www.ittakesguts.org.uk/share/in-my-shoes-app

Useful links

Crohn's and Colitis UK www.crohnsandcolitis.org.uk CCUK Talking Toolkit www.ittakesguts.org.uk/talk/talking-toolkit It takes guts www.ittakesguts.org.uk







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This information sheet was created from the things young people said were important in our 'Being Me with IBD' Study. The study was funded by Crohn's and Colitis UK.