

Support for IBD kids



With consultation, understanding and support, students with inflammatory bowel disease can experience all the benefits of schooling.

BY MARGARET BOZIK



BRIEFLY

75,000 Australians have been diagnosed with inflammatory bowel disease.

IBD can disrupt physical development, education and participation in extracurricular activities.

A new booklet is available to help educators support students with IBD.

With one in 250 Australians aged 5-49 now diagnosed with inflammatory bowel disease (IBD), most teachers will inevitably encounter a student or colleague with the condition.

Crohn's disease and ulcerative colitis - the predominant IBDs - are often thought of as 'young person's diseases' because diagnosis is typically in adolescence and early adulthood, says Francesca Manglaviti, CEO of Crohn's & Colitis Australia (CCA). In recent years, however, IBD has been found more and more often in young children.

For this reason CCA has developed an information booklet, 'Students with IBD: A guide for primary, secondary and tertiary educators', aimed at helping educators support students who have IBD. It includes information about Crohn's disease and ulcerative colitis, their physical and emotional impact on students, and their effects on various aspects of life.

IBD is an autoimmune disorder that affects parts of the digestive tract, most commonly the small and large intestines. The body's immune system mistakenly attacks its own tissue, causing inflammation, or a 'flare'.

"Australia has one of the highest rates of incidence of IBD in the world," says Manglaviti. "It is becoming more prevalent, more complex and more severe, and each year more and more young people are being diagnosed."

"More than 75,000 Australians have IBD and 14 new cases are being diagnosed every day. The latest research suggests that, by 2022, there will be 100,000 Australians with IBD."

Despite the prevalence, Crohn's disease and

ulcerative colitis remain largely hidden diseases. Very few people are comfortable discussing a chronic and lifelong illness with symptoms that at times may include:

- diarrhoea
- urgent bowel movements
- abdominal pain
- fatigue
- rectal bleeding
- weight loss.

At this stage there is no cure for IBD, but the symptoms and the underlying inflammation are treated with a range of medications, and surgery in some cases.

"Many people with IBD live very normal lives," says Manglaviti.

"But students will most likely experience a disruption to their education, extracurricular activities and social life."

"Schools play a crucial role in helping these students live normal lives, while a lack of involvement and support from the school can lead to problems such as diminished academic performance, difficulties maintaining relationships and a lack of confidence, motivation or self-esteem."

Candid discussion

CCA encourages carers of children with IBD to have an open and candid discussion with the school as soon as possible after diagnosis or at the start of the school year. The school, in consultation with the family and clinical team, should develop a student health support plan, accessible by all staff, including relief teachers, prior to commencing work.

"The plan is very important," says Sue Baker, the mother of six-year-old Charli, who attends a NSW public school and lives with a stoma bag



following surgery for IBD. "Before Charli started school, I arranged a meeting with the principal, vice-principal and classroom teacher. I have had three meetings with the school to update and revise how Charli is going, which has all been recorded on paper.

"As Charli has an ileostomy [a surgically created opening], she also has a teacher's aide to help empty her bag three times a day. Charli was placed in a kindergarten class with a toilet attached, which has been fantastic.

"Her teacher's aide is very discreet and doesn't sit just with Charli in class, but helps all the children so no one thinks she is only there for Charli."

Charli is treated no differently from the other children and has settled into school very well, says Baker.

"She took the book *Toilet Paper Flowers* to school. It's about a little girl with Crohn's disease, and she wanted her teacher to read it. As Charli is in kindy, the other children don't know much about her illness, but this book is a good place to start."

Baker says IBD is tricky because it's a 'hidden' disease. "I know parents who have had difficulties with their school because the child may look all right on the outside.

"It must be stressed to every teacher and staff member at the school that IBD children get tired very easily, may lack concentration, may have slower fine-motor skill development, may have pain they are dealing with on a daily basis and may need to run to the toilet at a moment's notice. Also, there are many, many side effects of IBD medications they need to be aware of."

PLAINPICTURE



Many people with IBD live very normal lives, but students will most likely experience a disruption to their education, extracurricular activities and social life.

Francesca Manglaviti
CEO, Crohn's & Colitis
Australia



Find out more

- crohnsandcolitis.com.au
- 'Students with IBD: A guide for primary, secondary and tertiary educators' - available free of charge, phone 1800 138 029
- [facebook.com/crohnsandcolitis](https://www.facebook.com/crohnsandcolitis)