

IBD in children and adolescents

In the past, IBD tended not to be considered in children and adolescents: many people felt that it did not occur in young children. In fact, IBD can occur in children of any age and is becoming more common in New Zealand and elsewhere in the world.

The impact of IBD in a young child, and upon their family, can be dramatic and long-lasting. Many important aspects of IBD in childhood are quite different from the situation in adults.

Can IBD develop in children?

Both Crohn's disease and ulcerative colitis can develop in children of any age, right down to the first months of life. However, IBD is uncommon in preschool children and becomes more common as children grow older. The most common age of diagnosis in childhood is in early adolescence, from around 12 or 13 years.

Over recent years, as IBD has become more common in many parts of the world, rates of IBD have increased dramatically in children. Several reports show that children are developing IBD at younger ages than before. As in adults with IBD, Crohn's disease and ulcerative colitis in childhood are long-term and ongoing conditions once they have started.

How does IBD present in children?

Children with IBD can have a wide range of symptoms before diagnosis. Common symptoms in children with Crohn's disease are abdominal pain, diarrhoea and weight loss.

The most common symptom in children diagnosed with ulcerative colitis is diarrhoea with blood. However, children can have a number of other symptoms before diagnosis. These may include weight loss, reduced growth, mouth ulcers, rashes, sore joints, fatigue, anaemia, iron deficiency, and, rarely, swelling of the lower lip.

Some children will just experience reduced growth without any bowel symptoms, whilst others will just have abdominal symptoms. Considering IBD as a potential cause for various symptoms is important.

Can IBD interfere with growth and development?

One of the important aspects of IBD in children and adolescents is the potential impact of the bowel problems upon growth, nutrition and pubertal development. Most children with Crohn's disease have problems at diagnosis gaining weight or with weight loss. These problems can also be ongoing after diagnosis in many children.

Many children with IBD, especially those with Crohn's disease, can also have difficulty growing taller. Children may notice that their classmates are growing taller whilst they are staying the same. Some may end up shorter than expected for their family if the diagnosis or adequate treatment is delayed. Usually, however, children and teens experience a growth spurt once their disease comes under control.

Also, because IBD commonly causes problems just before or through adolescence, it may impact on the onset and progression of puberty. Prompt diagnosis at presentation, along with close and careful attention to growth and

nutrition is important to ensure normal development.

As well as impairing growth, IBD can interfere with other aspects of nutrition. For instance, vitamins and minerals may not be absorbed or made available in adequate amounts. Two common examples are iron and vitamin D.

How is IBD diagnosed in children and adolescents?

After IBD is considered as a possible cause of a child's symptoms, the standard approach includes blood tests (to look for signs of inflammation and to show how well the gut is working and absorbing nutrients) and stool tests (to rule out infections and to detect gut inflammation). If IBD seems likely, the next step will likely include both a gastroscopy and a colonoscopy.

A gastroscopy is a procedure in which a flexible tube with a video camera is passed through the mouth into the stomach and the beginning of the small intestine. A colonoscopy is a similar test to check the large intestine (colon) and the very end of the small intestine. These examinations are usually performed under general anaesthesia so there should be no pain or discomfort. At the time of these procedures, biopsies (samples) can be taken from the inside lining of the intestines to confirm the diagnosis of IBD.

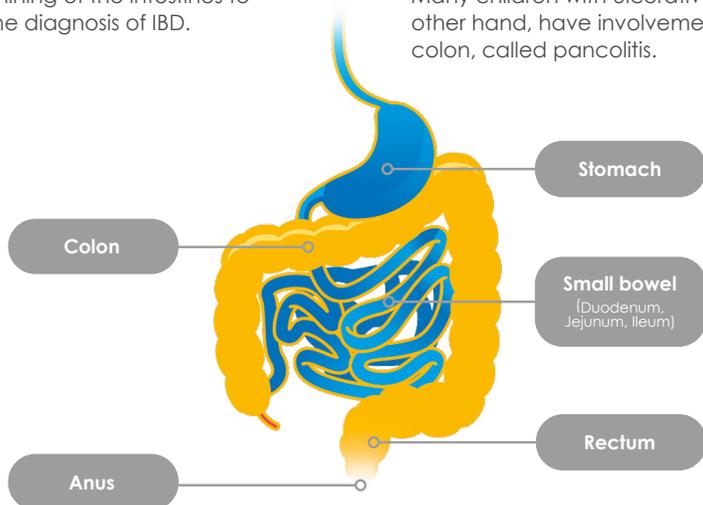
Another test may be required to examine the rest of the small bowel that can't be seen with the above tests. An MRI or another type of X-ray test might be undertaken, depending on what is most appropriate. Because of the pattern of IBD in children, it is very important to look at all areas of the gastrointestinal tract.

In what ways is IBD different in children than in adults?

A number of significant studies have shown that IBD beginning in childhood differs from that in older people in many ways. The onset of disease in children can be more severe than in adults and more difficult to manage.

Crohn's disease in children very commonly involves the upper parts of the bowel – the oesophagus, stomach and upper small bowel – which are not commonly affected in adults. Because this is the part of the digestive tract that is most important in the absorption of food and nutrients, changes in these areas can cause nutritional deficiencies and interfere with growth.

Ulcerative colitis in children also tends to be much more extensive than in adults. Very few children, for instance, have involvement of just the lower section of the colon, called proctitis, while this is common in adults. Many children with ulcerative colitis, on the other hand, have involvement of the whole colon, called pancolitis.





How should IBD be managed in children?

After diagnosis with IBD, it is important that the child diagnosed with IBD receives information and resources that are appropriate for their age. The initial education process is just as important for parents, caregivers and other family members. Many opportunities to answer questions and provide clear information are often required.

A child's understanding of the complexity of IBD will vary according to their age. Clearly, a toddler will understand things very differently from a teenager. In addition, learning about IBD for a child is an ongoing process. A child's needs and their questions will vary as they grow older.

The management of IBD in children and adolescents requires a broad approach. Although an initial focus will be upon settling down the active inflammation and getting control, ongoing management

needs to focus on maintaining remission (keeping control of inflammation), growth, development and avoidance of treatment-related complications.

It is also important that the child or adolescent is able to return to and then maintain normal age-appropriate activities. Attention to how the child is coping and managing their disease is particularly important.

As above, there are many aspects to the care and management of children and adolescents with IBD. Consequently, many people need to be involved in their care. As well as a general practitioner, the central person for a child with IBD will be their paediatric gastroenterologist. Some young people will also have a paediatrician involved. Other people commonly involved include an IBD nurse or other nursing staff, a dietitian, a psychologist and a social worker. Some children may need to see a paediatric surgeon if an operation is considered.

Regular visits will include review of growth (measurements of weight and height and plotting them on a growth chart), checking for symptoms, and making sure that medications are tolerated and working well. These are also important times for children or their parents to ask questions and for the medical team to make sure that children understand their treatments and are learning about their IBD.

Generally, paediatric centres look after children with IBD until around the end of secondary school. At that time, young people will transition their care to an adult gastroenterologist or to a joint transition clinic after a period of preparation. This can be a difficult time for young people and for their parents as it also coincides with many other life changes, such as moving from school to work, or from school to university.

What treatments will children with IBD need?

A variety of treatments are available for children with Crohn's disease and ulcerative

colitis. Many of these are also used commonly in adults with IBD (please see the Medications section).

Choices of medications take into account the child's pattern of IBD and their disease severity. Side effects can occur with different therapies and these must be considered carefully in light of the benefits of the therapy. Learning about the different medicines is another part of understanding IBD and is important for young people and their parents.

Generally, the treatments used in children can be divided into those used to get the disease under control (get into remission) and those used to keep it in control (prevent relapse).

Some common treatments to get IBD under control are nutritional therapies, steroids (e.g. prednisone) and antibiotics (such as metronidazole).

Steroids have traditionally been used regularly in children of different ages to gain control of active disease. A higher dose is used initially, which is then progressively decreased every one to two weeks until they are ceased. Steroids are not used long term in children. It is now clear that, while steroids can settle down symptoms, they do not help to heal the surface of the bowel and are linked with various short and potentially long-term side effects. Steroids are still used in children, but doctors will often prefer to try other options first in order to avoid them (and particularly to avoid repeated courses).

Antibiotics can be used for particular types of Crohn's disease, such as oral changes or

involvement around the bottom. They can also be helpful for active Crohn's disease of the large bowel. They tend to be used less for ulcerative colitis.

Nutritional therapy, also known as exclusive enteral nutrition (or EEN), is a very effective therapy that involves the use of special drinks (formulas) that are like milkshakes. These drinks need to be taken without any ordinary food (exclusively) as a complete diet, ideally for at least eight weeks.

This approach is especially helpful in Crohn's disease but can also have a role in ulcerative colitis. This treatment is as effective as steroids in achieving control of disease but leads to much more effective healing of the lining of the gut and avoids any side effects related to steroids.

As well as anti-inflammatory effects, enteral nutrition is also beneficial for nutrition and growth. This therapy tends to be more effective when used as the first treatment for Crohn's disease, but it can still be very helpful in children who have had Crohn's disease for some time. Enteral nutrition can also be used to help maintain control of Crohn's disease – in this case it is used as a supplement along with a normal diet.

Other medicines used to keep control include aminosallylates (e.g. Pentasa® and Asacol®) and immunomodulator medications (azathioprine, 6-mercaptopurine or methotrexate). These medications are used long term, often beginning soon after diagnosis.

Aminosallylates (5-ASA) are often used in children and adolescents as they tend to have few side effects. They can help in



Nutritional therapy, also known as exclusive enteral nutrition (or EEN), is a very effective therapy that involves the use of special drinks (formulas) that are like milkshakes.

keeping control of symptoms, particularly in ulcerative colitis. They are often not strong enough by themselves for children, however.

Many children need to have an immunomodulator to keep control of their IBD and to prevent relapses or other problems. In most centres, around two-thirds of children are on one of these medications. These medicines potentially have more side effects, but careful monitoring and appropriate dosing schedules can help to ensure that they are as effective as they can be, and that side effects are prevented or avoided. Despite the fact that these medications are very effective, they do not work for every child.

Biologic therapies have been available since the early 2000s. These medications are antibodies that are directed to part of the inflammation process. Infiximab and adalimumab are two of these medications that are currently available in New Zealand; both are antibodies that are directed to halting the activity of a protein called TNF. These medications have roles in children with severe disease, especially Crohn's disease.

Many other medicines can be used for Crohn's disease and ulcerative colitis when disease is severe and standard medications are not helping. Examples are tacrolimus, cyclosporine and mycophenolate.

Although some children or adolescents with IBD do need to have an operation, this is less common than in adults. Some children with extremely severe ulcerative colitis who

don't respond to any of the standard treatments have needed to have an operation.

In Crohn's disease, surgery would typically be considered to remove a section of bowel that is not responding to other treatments and is causing problems (such as a narrowing at the end of the small bowel causing blockages and pain). In this instance, surgery would be considered to solve the problem, but it needs to be remembered that surgery cannot cure Crohn's disease.

Overall, surgical techniques have improved significantly in recent years. The increased use of keyhole surgery (laparoscopy) means that surgeons can get their job done with smaller incisions, which result in smaller scars, less pain and faster recovery afterwards.

Do children with IBD need a special diet or special nutrition?

Overall, most children should continue with a well-balanced diet after diagnosis of Crohn's disease or ulcerative colitis. Generally, children should be encouraged to have a diet containing whole foods and avoid processed foods (especially highly processed foods with many additives). The exclusion of particular food components is not generally helpful and can impact adversely and significantly upon children's overall growth and wellbeing.

Some children with active Crohn's disease involving their small bowel can have temporary difficulties tolerating lactose (the sugar in milk and other dairy products). At



Children should be encouraged to have a diet containing whole foods and to avoid processed foods.



these times, foods that don't contain lactose should be used instead of standard cow's milk-based products. These include lactose-free cow's milk or soy products.

Some children with a stricture (narrowing) in the small bowel should exclude foods with high residue, such as corn or popcorn, which could become stuck.

Some children need nutritional supplements in order to prompt and enhance growth. These might include extra high-calorie drinks each day, or having these drinks delivered overnight via a nasogastric tube (tube from nose to stomach) or sometime via a gastrostomy (tube directly into the stomach through the skin). Sometimes children with growth failure or delayed growth spurts will need this help over a long period, but the benefits will be significant.

Each child with IBD should have regular reviews of their growth and routines with an experienced paediatric dietitian. The dietitian will be able to check that the child's diet is adequate and will be able to provide advice to help with beneficial extra foods. The paediatric dietitian will also be able to help with advice with diet during flares or relapses. Many children will need extra vitamins or minerals because of low levels. Common deficiencies include iron, zinc and vitamin D; less commonly, levels of vitamin B12, folate, magnesium and vitamin C can be low, requiring correction.

Calcium supplements are also often given – these are needed to build strong bones.

Bones can become thin and more fragile as a consequence of low calcium, low vitamin D and active inflammation. Steroids also lead to thinning of bones.

Do children cope better with IBD than adults?

Many people with Crohn's disease and ulcerative colitis can have difficulty coping with their disease, and children are no exception. Some children can become anxious, while some can become depressed. Some find lack of growth in puberty very distressing.

Providing education and developing skills to cope with IBD is important. Children can often obtain support from other children with IBD; with electronic connections widely available these days, this can be via email or social media, as well as in person.

Joining others at Camp Purple Live can also be very helpful and powerful for children. Camp Purple Live is an annual six-day camp for children and teens with Crohn's disease and ulcerative colitis. They meet others who understand the challenges of these diseases, see that they are not alone, learn coping skills, and many make lifelong friends. A staff of 10 medical professionals are present on site 24/7. The camp is free, as is a two-day seminar that runs concurrently for parents and caregivers (see the links at the end of this chapter for more information).



Access to a paediatric clinical psychologist can be important for a child with IBD. A psychologist can help children to learn skills and ways to help them cope with their condition. In addition to these preventative strategies, a psychologist can be important when children are having trouble coping.

Should children with IBD continue normal activities and schooling?

Most certainly! The overall objective of managing IBD in young people is to make sure they are doing all the things that they want to do and they are not limited in any way. Generally, if a child is unable to get to school or play sport, it is because their disease is not well controlled; this is a signal that the treatment needs to be revised.

More information about school and sports is contained in the 'School, sports and IBD' chapter.

Can children read about their condition on the web?

There are many excellent sites on the internet that focus on issues facing young people with IBD; however, there are also

many inappropriate sites. If parents are unsure, they should check with their child's medical team. Some examples of good sites for young people are:

GI KIDS: <https://gikids.org/>

CCFA: <https://www.crohnscolitisfoundation.org/youth-parent-resources>

Crohn's Colitis Canada: <https://crohnsandcolitis.ca/Living-with-Crohn-s-Colitis/If-your-child-has-Crohn-s-or-colitis>

CC UK: <https://www.crohnsandcolitis.org.uk/about-crohns-and-colitis>

Camp Purple Live and Parent's Seminar:
campenquiries@crohnsandcolitis.org.nz
<https://crohnsandcolitis.org.nz/camp-purple-live>

<https://ibdandme.org/>

<https://www.ibdandme.org.nz/>

<https://www.ownyouribd.co.nz/>

<https://pedsibd.org/>

<https://www.cicra.org/>