

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. 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 to the situation in adults.

Can IBD develop in children?

Absolutely! 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 with age. 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, 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 include losing weight, not getting taller, mouth ulcers, rashes, sore joints, lethargy, anaemia, iron deficiency and lip swelling. Some children will just have trouble getting taller without any bowel symptoms, whilst others will just have tummy 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. Almost all children with Crohn's disease have problems at diagnosis gaining weight or weight loss – more than half of children with ulcerative colitis also have these problems. In lots of children these problems can be ongoing after diagnosis. 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 or not effective. In the past, many young people who were diagnosed with IBD in adolescence, ended up being stunted (i.e. being short as an adult).

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

As well as impairing growth overall, IBD can commonly

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), stool tests (to rule out infections) and other stool tests to detect gut inflammation. If IBD seems likely, then the next step will include both upper gastrointestinal endoscopy (gastroscopy) and colonoscopy, along with many biopsies from the surface of the bowel. A further test will also be required to examine the part of the small bowel that can't be seen by the scope test. An MRI or another type of x-ray test might be undertaken, depending on what is most appropriate for the circumstances and what is available locally. Because of the pattern of IBD in children, it is very important to look at all areas of the bowel.

The diagnosis of IBD is then made from the findings on the surface of the bowel, along with the findings from the biopsies.

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. Several studies show that different gene changes can be seen in young children. Preschool onset of disease tends to be severe, and difficult to manage. IBD in childhood and adolescence has the potential to impact severely upon growth and development. Even diagnosis less than 20 years is shown as an important risk factor for more severe disease and for more intensive medications.

Crohn's disease in children very commonly involves the upper parts of the bowel – the oesophagus, stomach and upper small bowel. Given that the upper parts of the gut are important in digestion and absorption of food and nutrients, changes in these areas can impair these activities. This emphasizes how important the initial tests might be and also emphasizes the impact of Crohn's disease upon growth. Involvement of just the terminal ileum tends to be less common than in adults.

Ulcerative colitis in children tends to be much more extensive than in adults. Very few children have involvement of just the last section of the bowel (called proctitis), whilst this is quite common in adults with ulcerative colitis. Many children with ulcerative colitis have involvement of the whole colon. Those who don't have this pattern at the beginning tend to have extension of their disease rapidly over the first years after diagnosis.

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. This initial education process is very important also for the parents and other family members. Multiple opportunities to answer questions and to provide clear information are often required.

A child's understanding of the complexity of IBD will vary according to their age and developmental stage. Clearly a toddler will understand things very differently from a 13 year old. 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 the active inflammation down 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: as well as school this may include sports or other activities. Attention to how the child is coping and managing their disease is also important.

As above, there are many aspects to the care and management of children and adolescents with IBD. Consequently, many people are usually involved in the care of children with Crohn's disease and ulcerative colitis. As well as your general practitioner, the central person for children with IBD will be their paediatric gastroenterologist. Some young people will also have a paediatrician helping in their care, usually in a shared care with their paediatric gastroenterologist. Other people who are commonly involved include an IBD nurse or other nursing staff, a paediatric dietician, a psychologist and a social worker. Some children will also see a paediatric surgeon at times when an operation is considered.

Regular visits will include review of growth (measurements of weight and height, and plotting on appropriate growth charts), checking for any symptoms and to make sure that things are well controlled, checking that there are no side-effects or complications 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 learn 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. 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 chapter for more information). 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 always need to 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 into control are: steroids (e.g. prednisone), nutritional therapies and antibiotics (such as metronidazole).

Steroids have traditionally been used regularly in children of different ages to get control of active disease. They are used at a higher dose initially and then progressively decreased every 1-2 weeks until they are ceased. Steroids are not used long-term in children. It is now clear that although steroids can settle down symptoms, they are not very good at healing the surface of the bowel and are linked with various short and potentially long-term side-effects. Steroids are still used in children, but many times doctors will try other options in preference to avoid steroids (especially 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 don't tend to have a role for ulcerative colitis, however.

Nutritional therapy, also known as exclusive enteral nutrition, 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 8 weeks. This approach is very helpful in Crohn's disease, but is not as helpful 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 also has great benefits upon 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 aminosaliculates (e.g. Pentasa[®]), and immunomodulator medications (azathioprine, 6-MP or methotrexate). These medications are used long-term, often from just after diagnosis.

The aminosaliculates are often used in children and adolescents as they tend not to have many side-effects. They can help in keeping control of symptoms, particularly in ulcerative colitis. Many times they are 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 these medications being very effective, they do not work for every child.

Since the turn of the century, the so-called biologic therapies have become available. These medications are antibodies that are directed to a particular protein involved in gut inflammation (TNF). Infliximab and adalimumab are two of these medications that are currently available in New Zealand. These medications have roles in children with severe

disease, especially Crohn's disease.

There are many other medicines that can sometimes be used for Crohn's disease and ulcerative colitis, when disease is severe and standard medications are not helping. Examples are tacrolimus, cyclosporin 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 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 surgery cannot cure Crohn's disease. Over time, a number of people with ulcerative colitis will have their colon removed (colectomy), but this is less common through childhood.

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

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

Overall most children should continue a good, well-balanced, diet after diagnosis of Crohn's disease or ulcerative colitis. Exclusion of particular food components is generally not helpful and can impact adversely and significantly upon children's overall growth and well-being.

Some children with active Crohn's disease involving their small bowel can have temporary difficulty tolerating lactose (the sugar in milk and other dairy products). At 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 defined stricture (narrowing) in the small bowel should exclude foods with high residue such as corn or pop-corn that could get stuck.

Some children do need nutritional supplements in order to prompt and enhance growth. These might include having 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 for a long time, with great benefits.

Each child with IBD should have regular reviews of their growth and regular routine reviews with an experienced paediatric dietician. The dietician will be able to check that the child's diet is adequate, and will be able to give ideas to help with beneficial extra foods. The paediatric dietician will also be able to help with advice with diet during flare-ups or relapses.

Many children will need some 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, needing 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: children are no exception. Children can become anxious whilst 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 get support from other children with IBD – nowadays with electronic connections this can sometimes be via email, or facebook, as well as in person.

Access to a paediatric clinical psychologist can be important for children 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 that they are doing all the things that they want to do and to make sure that they are not limited in any way. Generally if a child is unable to get to school or to play sport, then it is because their disease is not well controlled: this is then a signal that the treatment needs to be revised.

More information about school and sports is contained in the next chapter.

Can children read about their condition on the web?

There are numerous excellent sites on the internet that focus on issues facing young people with IBD. There are also many inappropriate sites. If unsure you should check with your medical team. Some examples of some good sites for young people are:

www.ucandcrohns.org

www.kidsibd.org

www.reachoutforyouth.org

North American Society for Paediatric Gastroenterology, Hepatology and Nutrition:

www.naspghan.org/index.cfm
(Family Resources)

This information is for general informational purposes and does not constitute medical advice. Please seek information and advice regarding your condition and/or treatment from your doctor.



Crohn's & Colitis New Zealand Charitable Trust
PO Box 22280, Khandallah, Wellington 6441, New Zealand.
Email: Info@crohnsandcolitis.org.nz
www.crohnsandcolitis.org.nz