



# IBD in Children & Adolescents

## CCSG Information pamphlet No. 7

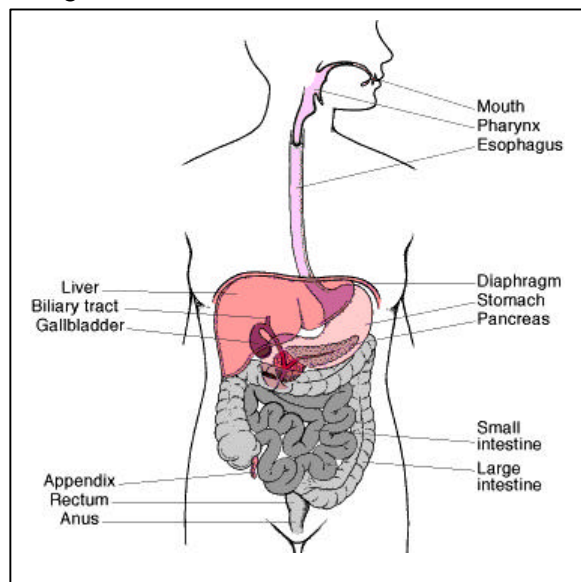
© Crohn's & Colitis Support Group (CCSG) Inc., 1999

This booklet sets out to answer the questions most commonly asked about the impact of inflammatory bowel disease (IBD) on children and adolescents. Crohn's disease and ulcerative colitis are primarily diseases of young people. 15% of patients with ulcerative colitis develop it before age 20 and for Crohn's disease the figure is closer to 30%.

It is not unusual for ulcerative colitis and Crohn's disease to be diagnosed in infants.

Crohn's disease and ulcerative colitis are chronic digestive diseases known together as inflammatory bowel disease (IBD). Crohn's disease can affect any part of the gastrointestinal tract. Patches of inflammation occur with healthy tissue between the diseased areas. Inflammation can affect every layer of the bowel.

Ulcerative colitis affects only the inner lining of the colon and rectum. The disease



*The gastrointestinal tract*

always starts in the rectum but may extend in a continuous fashion into the rest of the colon.

In both diseases symptoms include diarrhoea, abdominal pain, rectal bleeding, and fever. Loss of appetite and weight are common. The onset of these diseases may be rapid or insidious, and surgery may be required. Their cause and cure remain unknown. However, ulcerative colitis may be eliminated completely by surgical removal of the colon.

### ***Are Crohn's disease and ulcerative colitis different when they appear in children compared to adults?***

These diseases appear to be the same in children except that the symptoms of both seem to be more pronounced than in adults. Generally children with Crohn's disease have more abdominal pain, and growth and weight loss problems. In ulcerative colitis the predominant symptom is bloody diarrhoea. Treatment needs to be selected with special care when IBD appears in childhood. Another difference is that growing children with these diseases run a substantial risk that their growth may be slowed or interrupted. Because of this, physicians treating children with IBD must consider the impact on the child's growth before deciding on a course of medical or surgical treatment. While the drugs used to treat these illnesses, including sulfasalazine, mesalazine, antibiotics, corticosteroids and immunosuppressives, are the same for children and adults, the way these drugs are used may not be the same. For example, prednisone may be given to children in higher doses for brief periods during flare-ups, or if required over a longer period may be given on alternate days, to avoid interfering with growth.

### ***What are the early signs of these illnesses in children?***

In many children, the first signs of ulcerative colitis are a progressive loosening of the stool which is often bloody, and occasional abdominal pain. The diarrhoea may develop slowly or come on quite suddenly. In Crohn's disease, the early signs are often vague and early diagnosis can be much more difficult.

Abdominal pain is sometimes the most common early sign, appearing long before any diarrhoea. In others, the crampy pains and loose stools appear together. The pain is felt over the navel or on the right side, and often follows a meal. This unexplained abdominal pain together with loss of appetite and weight may be incorrectly diagnosed as anorexia nervosa, fear of attending school, or other psychological problems.

Less often, a child may complain of joint pains and fever long before gastrointestinal signs are present. Other early signs of Crohn's disease include sores in the anal area (skin tags, haemorrhoids, fissures (cracks), fistulas (abnormal openings from bowel to skin surface), abscesses, etc.

The most puzzling early sign of IBD in a child can be the appearance of growth failure months or even years before any other signs are present. This subject is discussed in later questions.

### ***At what ages do children develop these diseases?***

Children may develop either of these diseases at any age. IBD is being diagnosed increasingly in children under 10 years old. After age 10, the diseases increase in frequency, and the majority of all cases of both diseases have their onset between the ages of 15 and 30. Boys and girls appear to be affected equally, although Crohn's disease is slightly more common in females.

### ***What other symptoms do the diseases cause?***

Apart from growth failure, which is the major complication associated with IBD in children, the same complications that affect adults also affect children. (See CCSG Information Leaflet No.6 - *Complications* for more information). Non-intestinal complications tend to occur less often in children, but can often be the first sign of illness. For example, children can be treated

for arthritis years before the onset of abdominal symptoms.

### ***Do children ever outgrow these illnesses?***

Both Crohn's disease and ulcerative colitis are considered chronic diseases that persist, more or less, throughout life. However, many people with the diseases, children and adult, enjoy long periods of time when they are free of symptoms. Many people have only mild symptoms and many respond well to medical treatment, whether initial symptoms are mild or severe. The tendency to flare up occasionally means that escalation of treatment is required from time-to-time. Crohn's disease and ulcerative colitis are not considered fatal illnesses.

In addition, should a child with ulcerative colitis ever become ill enough to require surgery, removal of the colon and rectum is a permanent cure for this disease. Sometimes this will result in the formation of an ileostomy but more often the formation of an internal pouch. See CCSG Information Leaflet No.9 - *Surgery in IBD* for more information.

Surgery (usually a resection, or removal of the diseased portion of bowel) is often necessary for Crohn's disease as well, and can often provide the child or adolescent with many disease-free years. Surgery is not considered a cure for this disease.

### ***Can a paediatrician manage the disease, or does my child need to see another specialist?***

This depends upon whether your child's paediatrician is knowledgeable about IBD. It also depends on how sick your child is. In most cases, you will need to consult a gastroenterologist or a paediatric gastroenterologist. A paediatric gastroenterologist is a paediatrician who has received special training in the treatment of gastrointestinal diseases in children. Most gastroenterologists experienced in managing Crohn's disease and ulcerative colitis will treat children and adolescents with these illnesses, as will paediatric gastroenterologists.

For a young child or infant with IBD it may be more appropriate in some centres for the child to be under the care of a paediatrician in consultation with an adult gastroenterologist, ie. shared care.

### ***How can I tell if my child is not growing properly because of the illness?***

Growth failure occurs in about 15-30% of children with Crohn's disease and ulcerative colitis when the onset is before puberty. Signs of growth failure are poor or no increase in height and poor weight gain. A child may notice that he/she is shorter than other children in the same class. In addition, parents may notice that the size of a child's shoe, glove or clothing remains the same over a long period of time.

Your child's specialist can plot his/her growth curve on a chart. This should be done at 6-12 month intervals and shows the rate at which your child is growing compared with the average growth rate of other children across the country. This is a simple technique, and you may be shown how to keep track of your child's growth rate at home, using these same charts. An alert parent is often the first one to spot changes in a child's development.

Other signs of failure to grow are delayed bone development (which can be measured using x-rays) and delayed onset of puberty.

### ***What causes the failure to grow?***

While growth hormone is not deficient in children with Crohn's disease or ulcerative colitis, this problem is still being studied. It is known that these children, especially those with Crohn's disease, eat less than their bodies require because they are often not hungry. Furthermore, because eating triggers abdominal pain, nausea, and diarrhoea, they avoid eating to avoid pain. Researchers believe that this inadequate intake of calories, together with the nutritional depletion caused by diarrhoea, loss of dietary fat in the stool in some patients, and failure of the diseased bowel to absorb nutrients, are the most likely causes of growth failure in IBD.

Treatment with corticosteroids (prednisone) may also affect growth, but this effect can be diminished using an every-other-day treatment plan. Children with growth failure are often the sickest children. The evidence now suggests that the major factor affecting growth is how active the disease is. The more severe the disease and the longer it has been active, the more growth will be delayed. Often corticosteroid treatment will result in improved growth

because the disease is controlled and the child will eat better.

### ***What is the effect of surgery on growth failure in IBD?***

Surgery is often necessary in children when medical treatment fails to control symptoms, or when complications develop. Growth failure is sometimes considered an important indication for surgery, but only if the child has not yet reached puberty. Rarely, surgery is performed for growth failure alone if puberty has been delayed for several years.

Since Crohn's disease often recurs even after surgery, the decision to operate is rarely made because of growth failure alone. More often, surgery is performed because of complications such as obstruction, fistula formation, or poor response to medical treatment, combined with the failure to grow. Following surgery to remove diseased bowel, some growth retarded children resume growth while some do not. The reason for this difference is not known but they may just be naturally short.

### ***What about the onset of puberty? Will my child be normal?***

Follow-up studies of children with IBD have shown that even though puberty is delayed by several years because of the diseases, most teenagers eventually do reach maturity and function normally. Some of these teenagers, if they remain well, will continue to grow in height into their twenties, long after the onset of puberty, and long after their peers have stopped growing. Many reach their "normal" height in this way.

### ***Are there any special foods or vitamins that might be helpful?***

There are certain vitamins and minerals, for example vitamin B12, folic acid, vitamin C, iron, calcium, zinc, magnesium, which are often deficient in children with IBD. Some of these deficiencies can be identified and corrected by your child's physician. However, most researchers feel that simply getting the child or adolescent to eat (almost anything he/she feels like eating) is the first priority.

This is not easy as it sounds. Some children with Crohn's disease or ulcerative colitis develop uncomfortable symptoms such

as bloating, colic, and increased diarrhoea when they drink milk or eat products containing milk due to temporary lactose intolerance. This is a problem because these dairy products constitute the largest source of calories in the diets of children.

For children who have trouble eating, there are nutritionally complete liquid supplements, called elemental diets, which require little digestion and leave little residue for the bowel to excrete. These can be used alone or with regular food to increase caloric intake.

A technique to provide extra calories is the use of continuous infusion of a special formula at night. While the child is asleep, a nutritious supplement is pumped slowly into narrow tube passed through the nose into the stomach. This can be done at home, and helps to supply additional nutrition.

Generally, a low residue diet is best when there is a stricture, a high calorie diet for patients with growth failure, and otherwise a normal balanced diet.

### ***What if my child is too sick to eat?***

When a child can no longer take food orally, he/she can be fed all the necessary nutrients through a tube placed into a large vein. This method is called total parenteral nutrition (TPN). TPN can continue for weeks to rest the bowel and to improve the child's nutritional status and general health. Some children are prepared for surgery in this way, and have shorter convalescent periods as a result. Because their caloric intake is dramatically increased, many of these children begin to grow while they are being fed intravenously.

### ***How can I help my child to cope with this illness?***

Most important is your acceptance of your child's illness. Try to come to terms with it realistically. This will save your child the burden of trying to prove to you that he/she is ill. Try to become as well informed as you can. The CCSG provides information on inflammatory bowel disease to all that require it. Ask questions of your child's physician, and encourage your child to ask questions.

Some of the symptoms of IBD, such as severe pain or bloody stools, can be truly frightening to a young person. Your knowledge of these symptoms together with

your love and support can have a reassuring effect on your child. Feeling helpless or ignorant in the face of illness is never a help to anyone.

The impact of chronic illness in the family may cause you to spend more time with your ill child than with your other children. This can cause resentment and feelings of jealousy. Even though IBD in a child does tend to become a family problem, try if at all possible to avoid making the illness the centre of family life. This is often easier said than done.

### ***How much information should I give my child about his/her illness?***

Just as with education about sex, a child hears what he/she is ready to hear. Your child or teenager will probably indicate to you just how much information about the disease he/she is ready to hear. You should encourage your child to ask questions and to discuss concerns with their doctor. The physician can manage the illness better when he/she has a working dialogue with the child. Some children feel much more in control when they know the facts. One young teenager told her mother that she was able to face surgery without feeling panicky because her mother had spoken frankly about the illness, and about what was going to happen during surgery. Older children and adolescents have a right to know how the diseases will affect their lives and their bodies.

On the other hand, it is probably not a good idea to discuss with a young patient the full range of possible complications of IBD, many of which may never occur.

### ***Are there things that I do as a parent that can make things worse?***

First, there is nothing that you have done as a parent which has in any way caused your child's illness or made it worse. There is absolutely no reason for you to feel guilty. However, chronic illness in a child can cause parents to become overly protective. This is only natural, and a certain amount of protectiveness is essential for his/her well being. As soon as your child is old enough, it's a good idea to foster independence by encouraging him/her to take responsibility for some medical routines, such as taking

medications and calling the doctor when necessary.

The illness can become a source of tension between parent and child, coming, as it so often does, at an age where independence is a major issue. Some parents may become very alarmed when a child loses weight or eats poorly. Both children and adolescents need to voice their fears about changes in their bodies brought on by illness and treatments. These very real concerns are often difficult for parents to face. You and your child should discuss these concerns with your physician.

### ***Are there special problems facing teenagers with these diseases?***

Since adolescence is a time when physical appearance and acceptance by peers are extremely important, inflammatory bowel disease can pose a real threat to those teenagers affected by it. They often feel angry, depressed, and frustrated by repeated flare-ups which may require them to have extra rest. Their self-consciousness can lead to a degree of isolation. They resent the bodily changes brought on by the disease or by high-dose steroids. They may avoid visits to the doctor and fail to report symptoms or to take medications in an effort to deny that they are sick. However, a good relationship between doctor and patient is extremely important.

Since some of these young people will eventually have to have surgery, they may have real fears, expressed or not, about how they will function afterward. In some of these patients, their short stature may be an ever-present reminder of the illness, even when they are feeling fairly well. Of all the complications of IBD, this seems to be the one that causes the most distress.

Wherever possible children should be encouraged to take part in normal activities. Unnecessary dietary restrictions should be avoided eg. there is no evidence that people with IBD need to always avoid "junk" foods.

To help families cope with these problems, some physicians have developed a team approach to the treatment of IBD in the adolescent and routinely involve a social worker, psychiatrist, or other therapist in the treatment program. Many adolescents benefit from support groups of their peers, set up by branches of CCSG where they can voice the

concerns that are unique to them. Similar CCSG groups have helped parents of children with IBD who are seeking emotional support, information, and ways of coping with illness in the family.

### ***What do I do if my child becomes depressed about the illness?***

After a period of relatively good health, your child may suffer a setback and may become understandably depressed at the realisation that the disease is not going to go away. Changes in mood may also result from treatment with prednisone or other corticosteroids. You can help by reassuring your child that this setback is probably temporary, and by making sure your child receives prompt medical attention.

Some children and adolescents may benefit from the help of a therapist familiar with inflammatory bowel disease. Experience has shown that the depression is usually related to disease activity or to its treatment when the child begins to feel well enough to go on with normal activities, the depression usually lifts.

### ***Should a child with Crohn's disease or ulcerative colitis attend school regularly, or participate in sports?***

Young people with illnesses should be as active as they feel like being. There is no reason not to go to school or to participate in sports if the child feels well enough. However, some strenuous sports may cause fatigue or aggravate abdominal pain, arthritis or other symptoms. If this happens, a modified gym program may be the answer.

Children learn to accept a certain amount of pain and discomfort as normal in these illnesses and learn to live with it. They usually know when it gets to be too much. You should try giving your child the responsibility of determining whether or not he/she is able to go to school during flare-ups. Forcing school attendance or encouraging a child to spend many days in bed will both lead to tension in the family.

Encourage your child or adolescent to find practical ways of dealing with the illness in school. He/she can learn where the nearest bathrooms are, can visit the school nurse's office, and can carry extra underclothing.

***Should my child's friends and teachers be told about the illness?***

Your child or adolescent should decide whether to tell anyone about the disease. Since the diseases are difficult to explain, and since children can often be quite cruel about such things, your child may wish to protect him/herself by not telling friends about the illness. You should not interfere with his/her wishes.

However, if there are hospitalisations or frequent absences from school, teachers and/or school administrators should be told matter-of-factly about the child's illness. The CCSG's information leaflets can be used to accomplish this. Such explanations can make life easier when a child needs to make frequent trips to the bathroom, or needs to be out of school for long periods.

***What are the chances that my other children will develop this disease?***

It is possible, but certainly not inevitable, that another member of your family has, or will develop ulcerative colitis or Crohn's disease. Studies have shown that 10-35% of patients have a near relative with either of the two diseases. The percentage is higher when you count distant relatives. But even when the diseases cluster in families, there does not seem to be any clear-cut pattern. Because of this, the diseases are called "familial" and not "genetic".

Therefore, no one can predict whether a child will "inherit" the disease, and physicians do not discourage a couple from having another child, simply because there is inflammatory bowel disease in the family.