

## IBD: A guide for general nurses

### Summary

- Ulcerative Colitis (UC) and Crohn's Disease are common chronic forms of Inflammatory Bowel Disease (IBD). They have no proven cause, and as yet no cure.
- UC affects the lining of the large bowel (colon), causing inflammation that extends upwards from the rectum.
- Crohn's Disease can affect any part of the gastrointestinal tract, but most often involves the terminal ileum and/or the colon. Fistulae and abscesses, particularly around the anus, are common with Crohn's.
- Key symptoms of UC include diarrhoea, mucus, rectal bleeding, weight loss and fatigue. There is an increased risk of bowel cancer for people with longstanding UC and ongoing inflammation. The cancer risk is similar for those with extensive Crohn's Disease of the colon, but lower for those with Crohn's limited to the small bowel.
- Crohn's symptoms may also include diarrhoea, abdominal pain, weight loss and fatigue. Cigarette smoking is very detrimental.
- There are a number of extra-intestinal manifestations of IBD, some of which respond to medical treatment given for the IBD. Others require additional treatment.
- Drugs used for IBD include 5-Aminosalicylates (5-ASAs) such as mesalazine, which reduce bowel inflammation and are usually taken indefinitely. More severe attacks may be treated with corticosteroids, and/or immunosuppressants such as azathioprine. Anti-TNF drugs, such as infliximab and adalimumab, are now increasingly used for IBD, especially for Crohn's Disease.
- Changing the diet has little effect on UC disease activity, although a low residue diet may help with symptoms during an acute flare. Nutritional therapy (enteral feeding) can be a useful treatment option in Crohn's Disease, especially for children.
- Surgery for IBD is sometimes required. In UC this usually takes the form of a colectomy and stoma (ileostomy) or pouch formation (ileo-anal pouch and anastomosis). Surgery for Crohn's is most often for complications such as bowel strictures, fistulae and abscesses. Occasionally Crohn's patients may require an ileostomy or colostomy.
- Surgery can be a key anxiety for many patients. Other major concerns include quality of life, safety of drug therapies, access to toilets, and fertility and pregnancy issues.
- IBD can severely affect quality of life and psychological support and understanding are important aspects of patient care. Specialist practitioners such as IBD nurses and stoma nurses have considerable experience in this area and can often help with particular anxieties and concerns.
- Patient associations such as Crohn's and Colitis UK can also provide helpful information and support, for health professionals as well as for patients and their families.

## Introduction

Ulcerative Colitis (UC) and Crohn's Disease are the two most common forms of Inflammatory Bowel Disease (IBD). Sometimes it can be difficult to distinguish between the two conditions, and a diagnosis of indeterminate colitis or IBD unclassified (IBDU) may be given. In the UK, IBD affects approximately 1 in 250 people.

This guide has been produced to give non-specialist nurses information about IBD and to help enhance their role in the care of people with UC and Crohn's Disease. Further copies can be downloaded from the Crohn's and Colitis UK web-site ([www.crohnsandcolitis.org.uk](http://www.crohnsandcolitis.org.uk)) and shared with colleagues.

## The main characteristics of IBD

The causes of IBD are unknown. However, there is evidence of an interaction between genetic susceptibility and as yet undetermined factors in the environment. Between 5% and 35% of people with UC and Crohn's have a family member who is also affected.

Ulcerative Colitis affects the inner lining (mucosa) of the colon, extending upwards from the rectum for a variable distance. Symptoms depend on the extent and severity of the condition but usually include urgent and frequent diarrhoea, often with blood and mucus, abdominal pain, and in some cases fever and weight loss. Patients with colitis limited to the rectum (proctitis) may present with constipation.

Crohn's Disease affects all the layers of the bowel wall and can occur in any part of the gastrointestinal tract from the mouth to the anus. The small bowel alone is likely to be affected in about 30% of cases, the large bowel alone in 25% of cases, and both small and large bowel in 40% of cases.

Symptoms vary with the site affected but include abdominal pain, diarrhoea (with or

without bleeding), fever, weight loss and fatigue. Some people with Crohn's develop a bowel obstruction and suffer from vomiting and/or constipation. Abscesses, fissures, fistulae and fleshy skin tags may occur in up to 50% of cases and can be very troublesome. In children with Crohn's lack of appetite and malabsorption can lead to dramatic weight loss and, in the long run, poor growth and delayed sexual development.

IBD is a chronic condition with episodes of relapse and remission. A small number of people with UC may remain in long term remission after their first attack; however most are affected for many years. UC is rarely fatal and people with stable UC have a normal life expectancy.

In Crohn's, approximately half of all patients relapse in the first year after diagnosis, and about 70% of people with Crohn's will require surgery at some time. Smoking has been found to increase both the risk of severe disease and the frequency of relapse in Crohn's.

## Extra-intestinal Manifestations of IBD

A minority of people with IBD also have extra-intestinal inflammation, possibly due to altered immune function. Some associated conditions parallel disease activity, and respond to medical treatment of the bowel inflammation. However, others occur independently of the bowel disease and require specific treatment.

The most common extra-intestinal manifestations are:

- inflammation of the joints (arthritis, sacro-ileitis and ankylosing spondylitis)
- inflammation of the skin (erythema nodosum and pyoderma gangrenosum)
- inflammation of the eye (uveitis and iritis)
- inflammation of the liver (fatty liver and sclerosing cholangitis).

## Investigations

Due to the chronic nature of IBD, investigations may be frequent, but the results may not always be conclusive. This can be frustrating for the patient, who may spend large amounts of time at hospital, sometimes without obvious benefit.

The main types of investigation used for IBD are listed below:

- Blood tests to assess anaemia, nutrition, and the severity of inflammation (ESR and CRP)
- Stool tests
- Endoscopies, including colonoscopies
- Radiological tests including barium X-rays, ultrasound, CT and MRI scans.

## Drug Treatment

Four main classes of drug are used in the treatment of IBD: aminosalicylates, corticosteroids, immunosuppressants and biological therapies.

Aminosalicylates, or 5-aminosalicylic acid (5-ASA) derivatives, include mesalazine, sulphasalazine, olsalazine and balsalazide. These are regularly prescribed to reduce inflammation and maintain remission. Although they are usually in tablet form, some of these drugs can be given rectally by suppository or enema to treat conditions confined to the rectum or lower colon. Patients with UC on 5-ASAs are often encouraged to continue treatment even when in remission as such drugs have been shown to reduce the number of relapses and may also reduce the risk of bowel cancer. However, a small number of patients can be intolerant of these drugs causing headaches and worsening of their diarrhoea.

In more severe attacks, patients with IBD may be given corticosteroids such as hydrocortisone, prednisolone or budesonide. While effective in reducing inflammation, these steroids can have adverse side effects such as weight gain, fluid retention, and in some cases, mood swings or depression. Steroid use can

also lead to long term problems such as osteoporosis.

Immunosuppressive agents such as azathioprine, 6-mercaptopurine, or methotrexate may be introduced to reduce the inflammation and also the duration of steroid therapy. These drugs tend to be slow acting and may take up to four months to be fully effective. Ciclosporin, another immunosuppressant, is sometimes used to treat acute severe UC which is not responding to steroids. All immunosuppressants increase the risk of infection, and regular blood tests will be required to check for possible side effects, for example, bone marrow suppression.

Biologic or anti-TNF drugs, such as infliximab and adalimumab, are increasingly used in the treatment of severe active or fistulising Crohn's disease. Infliximab may also occasionally be used to treat severe UC. Infliximab is delivered by intravenous infusion; adalimumab by subcutaneous injection.

Antibiotics or analgesic, anti-diarrhoeal, or anti-spasmodic drugs may also be prescribed for some people with IBD, and supplements of iron, calcium and vitamins D and B<sub>12</sub> may be needed.

For further information see our booklet, *Drugs used in IBD*, and our series of Drug Treatment Information Sheets.

## Nutrition

A range of dietary issues may affect patients with IBD, and all patients admitted to hospital could benefit from a full nutritional assessment and appropriate referral to a dietitian or nutritional team. Adequate intake of a balanced diet can sometimes be difficult for people with UC or Crohn's. In some cases IBD may lead to anorexia if patients associate eating with unpleasant symptoms and so are reluctant to eat. Also, in Crohn's, the damaged small intestine may not fully absorb all the nutrients from food.

Some patients may have been avoiding foods valuable to the diet (such as dairy products) if they have found that these seem to make their symptoms worse. This can result in a deficiency of calcium, protein and vitamin D. A low-fibre diet is sometimes needed to help to reduce pain and lessen the chance of obstruction in patients with Crohn's affecting the small intestine. Reduced fibre intake may also be helpful during UC flare-ups.

Supplementary foods such as Ensure, Fortisip and Complan, or favourite foods from home can be helpful for some patients if they find hospital food unpalatable or are intolerant of certain foods.

For more information on healthy eating with IBD see our booklet: *Food and IBD*.

### **Nutritional Treatment**

An elemental or polymeric diet (complete nutrition in very easily digested liquid form) is sometimes used to treat intestinal inflammation in Crohn's Disease, especially in children. It is not particularly palatable, but can be administered by naso-gastric tube, if necessary. Intravenous feeding may be needed for very ill patients or in the peri-operative period.

### **Surgery**

Surgery can be very effective in some cases. The main indications for surgery are shown below:

#### **Ulcerative Colitis**

- Unresponsiveness to medical therapy
- Toxic dilatation of the colon
- Precancerous changes (dysplasia)
- Colorectal cancer

#### **Crohn's Disease**

- Unresponsiveness to medical therapy
- Peri-anal or intra-abdominal abscesses
- Intestinal stricture causing obstructive symptoms
- Intestinal perforation
- Fistula

The surgical procedures commonly carried out for UC, such as colectomy and proctocolectomy, may involve the formation of a stoma. In some cases it may be possible to create an internal ileo-anal pouch, so that the ileostomy is only temporary.

In Crohn's Disease the two most common operations are stricturoplasty and resection. Occasionally, people with Crohn's may require a colectomy or ileostomy and the formation of a stoma. Pouch formation surgery is not generally suitable for most people with Crohn's Disease. Fistulae may be treated with a fistulotomy or the insertion of a Seton stitch.

Additional information can be found in our information sheets: *Surgery for Crohn's Disease* and *Surgery for Ulcerative Colitis*.

### **Major Concerns of People with IBD**

#### **Access to toilets**

It is important for all hospital staff to appreciate that people with IBD may have urgency of defecation. Those needing help to the toilet need it immediately. Bowel actions are often explosive, noisy and malodorous. The use of a commode behind a curtain in an open ward can be embarrassing. Whenever possible, patients should have a single room with *en suite* facilities or their bed as close as possible to a toilet.

#### **Fertility/Pregnancy**

Most people develop IBD during their reproductive years and so fertility, pregnancy, and genetic predisposition to the disease are frequent concerns. Fortunately, the majority will have normal reproductive function and normal healthy babies.

While IBD does not necessarily affect fertility, some people with severe Crohn's may find they are less fertile, particularly if they are malnourished. Research has shown women who have had pouch surgery for UC may also have reduced

fertility. The 5-ASA drug sulphasalazine can lead to a temporary loss of fertility in males, although the newer 5-ASA drugs, (eg mesalazine) do not have this effect.

Effective control of IBD is an important factor in successful pregnancy, so women who become pregnant are generally advised to continue taking their IBD medication. The majority of medications used to treat IBD are considered safe in pregnancy. However, because of a risk of birth defects, methotrexate is absolutely contra-indicated not only during pregnancy but also at the time of conception. Taking other immunosuppressants during pregnancy should also be considered carefully by the patient and doctor, although there is very little evidence that these drugs are harmful.

Because biological therapies are still fairly new and the evidence for their safety in pregnancy is limited, the manufacturers of infliximab and adalimumab recommend that these drugs should be avoided by pregnant women. However, a panel of medical experts recently agreed that infliximab is safe to use in early pregnancy, and there have been several reports of successful pregnancies in women taking adalimumab. In some circumstances patients may now be advised by their doctors to continue with these therapies during pregnancy.

For additional details see our drug treatment information sheets on *Infliximab* and *Adalimumab*, and our leaflets *Fertility and IBD* and *Pregnancy in IBD*.

### **Stomas**

Many people with IBD find the idea of having a stoma particularly distressing. However, for some it can become the best option. The stoma care team should be involved early on to discuss anxieties and possible coping strategies. Once the stoma has been created patients are often surprised at the improvement in their quality of life.

### **Psychological Aspects**

IBD can occur in any age group, but most people present aged 10-40. As with any chronic disease, personal relationships, recreational activities and employment opportunities may all be affected. Comprehensive care should consider psychosocial factors as well as medical symptoms. Most people require accurate information about their condition and want to stay as much in control of their lives as possible. Help and support from the healthcare team can be an important factor in helping them achieve this.

Patients should be encouraged to talk to their doctors and nurses about any worries they may have. Specialist IBD nurses often have considerable experience of dealing with the psychological aspects of IBD. Other specialist practitioners, such as stoma nurses may also be able to help with advice about particular problems or anxieties. Additional counselling or other therapies may be helpful for people with significant anxiety or depression. We have an information sheet, *How can counselling help you?* which patients may find useful.

We also provide a general information line for any queries about IBD and a supportive listening service, NACC-in-Contact, which is staffed by trained volunteers with personal experience of IBD. (Contact details below)

### **Further information**

People with IBD often have more knowledge of their disease than non-specialist healthcare practitioners, so do not be afraid to ask the patient for information about how they manage their symptoms, or food preferences.

Further reading on gastrointestinal nursing can be found in:

- *Gastrointestinal Nursing*, by Graeme Smith and Roger Watson. Wiley-Blackwell 2005

- *Oxford Handbook of Gastrointestinal Nursing*, edited by Christine Norton. OUP Oxford 2008
- *Gastrointestinal Nursing*. A monthly journal for UK nurses specialising in gastro nursing and stoma care. MA Healthcare Ltd. See the website: <http://www.gastrointestinalnursing.co.uk>

Specialist practitioners within the IBD teams and patient associations such as Crohn's and Colitis UK, or IA (the Ileostomy and Internal Pouch Support Group) can also be useful sources of support and information, not only for patients and their families, but also for healthcare professionals.

**Crohn's and Colitis UK Information line:**  
**0845 130 2233, open Monday to Friday 10am - 1pm.** There is an answerphone service outside these hours.

**NACC-in-Contact Support Line:**  
**0845 130 3344, open Monday to Friday 1pm - 3.30pm and 6.30pm - 9pm.**

### **Other Organisations**

#### **IA (Ileostomy and Internal Pouch Support Group)**

Peveerill House, 1-5 Mill Road, Ballyclare, Co Antrim, BT39 9DR.

0800 018 4724 or 028 9334 4043

[www.the-ia.org.uk](http://www.the-ia.org.uk)

email: [info@the-ia.org.uk](mailto:info@the-ia.org.uk)

#### **Colostomy Association**

2 London Court, East Street

Reading, RG1 4QL

0800 328 4257 or 0118 939 1537

[www.colostomyassociation.org.uk](http://www.colostomyassociation.org.uk)

email: [cass@colostomyassociation.org.uk](mailto:cass@colostomyassociation.org.uk)

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***We hope that you have found the information helpful and relevant. We welcome any comments from readers, or suggestions for improvements. References or details of the research on which this publication is based can be obtained from Crohn's and Colitis UK at the address below. Please send your comments to Helen Terry at Crohn's and Colitis UK, 4 Beaumont House, Sutton Road, St Albans, Herts AL1 5HH, or email [h.terry@crohnsandcolitis.org.uk](mailto:h.terry@crohnsandcolitis.org.uk).***

**Crohn's and Colitis UK is the working name for the National Association for Colitis and Crohn's Disease (NACC). NACC is a voluntary Association, established in 1979, which has over 30,000 members and 70 Groups throughout the UK.**

**Membership of the Association costs £12 a year. New members who are on lower incomes due to their health or employment circumstances may join at a lower rate. Additional donations to help our work are always welcomed.**