Crohn’s disease has a significant impact on the lives of patients. New NICE guidance outlines evidence-based pathways of care

Crohn’s disease in adults and children

Crohn’s disease is one of a spectrum of inflammatory bowel diseases (IBDs) that can affect the entire gastrointestinal tract, but most commonly affect the small and large bowel. Symptoms of the disease can occur at any age but frequently start when patients are between the ages of 10 and 40 years. They include abdominal pain, diarrhoea, weight loss, fatigue and failure to grow in children.

The National Institute for Health and Clinical Excellence (2012) has recently published a guideline that provides information to clinicians on the latest evidence-based clinical and cost-effective care pathways for patients with Crohn’s disease.

**Patient information**
The guidance recognises that Crohn’s disease can have a significant impact on the lives of patients as well as their family members and friends.

Having information on the disease in a suitable format may help to reduce anxiety about it and encourage discussions about treatment options. Providing information on topics such as smoking cessation and medication adherence, which can reduce disease progression, is an important part of patient care. Side-effects, as well as expected benefits from the medications, should be discussed with patients, especially as some of the more frequently used drugs are used off label. These conversations should be documented in the medical notes.

Patients’ needs and preferences should be included in the decision-making process. This is particularly important when caring for children and young people as it is important to work in partnership with their family. Children should be included in all discussions about the disease and their treatment options where appropriate. The transition of care from paediatric to adult services is a process that needs to be managed in a timely and planned manner.

**Disease management**
As Crohn’s disease is relapsing and remitting in nature, the guidance looks at the processes involved in inducing remission.

In general, steroid therapy is used to gain disease control then consideration is given if further drug treatment, such as longer-term immunosuppression, is required to maintain remission. In the past, oral steroids were the main treatment for Crohn’s disease but these are no longer used because of long-term side-effects.

Where monitoring of the effects of treatment is required – for example blood monitoring for drugs such as azathioprine – it is important that a robust process is in place to ensure a suitable person is checking the results and able to take appropriate action if required. Some people may choose not to receive these medications. This may be due to concerns about side-effects so it is important to ensure patients have received enough information to make an informed decision. Their views should be respected and documented in the patient notes and ongoing follow-up provided.

People with Crohn’s disease may require surgery and it may be appropriate for them to undergo surgery early on (particularly when disease is limited to the terminal ileum) as this can limit exposure to long-term potent drug therapy. Surgical options include stricture balloon dilation, strictureplasty and resection. For children, it is important to consider surgery early in puberty to maximise growth potential.

Crohn’s disease can affect education, relationships, employment and child-bearing; it is important that appropriate advice is available throughout these experiences, particularly where treatments may affect outcomes, for example in bone health, growth and pregnancy.

**Specialist nursing care**
IBD nurses are well placed to support people with Crohn’s disease. Their experience and specialised knowledge, gained through advanced education and training, can offer a chance to enable patients to live as full and active a life as possible, with additional help available during times of disease relapse.

The guideline is available for download at www.nice.org.uk/CG152

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Reference

**Nursing Practice**

- **NICE guidance**
  - Crohn’s disease

- **Specialist nursing care**
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- **Reference**

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