A hidden disease

General practice continues to play an important role in educating young people with inflammatory bowel disease as its prevalence increases in Australia.

Crohn’s and colitis awareness

May is National Crohn’s and Colitis Awareness Month, during which Crohn’s and Colitis Australia aims to raise awareness about the diseases, which affect around one in 250 Australians.

Crohn’s and Colitis Australia is the peak national body that provides support services, funds research and creates public awareness of these chronic diseases.

Visit www.crohnsandcolitis.com.au for more information about the event or about the organisation.
Inflammatory bowel disease (IBD) currently affects more than 75,000 Australians. That number is projected to reach 100,000 by 2020, making general practice a vital first step in treatment.

‘Approximately one in 250 people has IBD and this means that GPs might expect to have at least three IBD patients in their practices,’ Dr Andrew Slutzkin, a Melbourne GP with a special interest in IBD, told Good Practice. ‘This is about the same prevalence as epilepsy and 3–4 times more common than HIV [human immunodeficiency].

‘The annual incidence of new cases is about one in 3000 people, so a GP might see a new presentation of IBD as often as once every one or two years.’

The most prevalent IBD conditions are Crohn’s disease and ulcerative colitis, which are commonly diagnosed in adolescents and young adults.

‘People often present with abdominal pain, loss of weight and pains. Some people will get diarrhoea and others surgical complication of the disease like bowel obstruction or abscess,’ Dr Greg Moore, a gastroenterologist and director of Crohn’s and Colitis Australia, told Good Practice. ‘Often, a lot of younger people will be labelled with having “school anxiety” or eating disorders.

‘It is a difficult diagnosis, but it is the job of the doctor to do a proper evaluation and get to the source of the symptoms.’

Crohn’s disease is a long-term, incurable disease that causes inflammation of the bowel and increases the risk of mortality by 47%. Ulcerative colitis is a disease characterised by inflammation and micro-ulcers of the large intestine and is only curable through surgery, but more severe cases can lead to death if untreated.

In Moore’s experience as Monash Medical Centre’s Head of Inflammatory Bowel Disease Unit, he has found relatively little research on the cause IBD.

‘We know that there is a genetic risk associated with Crohn’s disease and ulcerative colitis, but, through research with monozygotic twins, we also know that that alone is not enough,’ Moore said.

‘Environmental factors are very important and the basic thinking is that there is an ongoing, inappropriate immune response to what is a normal environmental trigger.’

**General practice management**

There is currently no single ‘gold standard’ test to establish Crohn’s disease or ulcerative colitis. Diagnosis frequently relies on a practitioner’s experience and investigative skills.

‘It is often a combination of tests,’ Moore said. ‘Clinical history is really important because Crohn’s disease is one of those IBD conditions that can affect anywhere from the mouth to the anus.

‘The GP really needs to be able to recognise the symptoms first and then order certain tests for confirmation.’

A 2012 study published in the Internal Medicine Journal surveyed 1800 Australian GPs and found 37% reported being ‘uncomfortable’ with the therapies involved in IBD management.

‘There are basic tests that you can do and, from a GP perspective, you need to exclude infection first,’ Moore said. ‘A good screening test that we recommend is called the “faecal calprotectin”. It is a good discriminator of an inflammatory gut disorder from a functional gut disorder like an irritable bowel syndrome, which can be hard to differentiate, particularly for Crohn’s disease.’

Crohn’s disease and ulcerative colitis often require several visits to the GP before being diagnosed and the patient can experience significant discomfort in the meantime.

‘Many new IBD patients describe a long lead time to diagnosis of six months or more,’ Slutzkin explained. ‘They might initially think they just have an upset belly or food intolerance. Once they see a doctor, it often requires a number of visits and/or second opinions before they are fully investigated and diagnosed.’

Slutzkin believes GPs, as the coordinators of care in their patients’ health and wellbeing, can benefit from being aware of current evidence-based information around IBD.

‘The GP should be the cornerstone of a person’s IBD management,’ he said. ‘While nearly all IBD patients will be under specialist care, with their medications instigated by IBD specialists, GPs will have a role in monitoring response to treatment and potential side effects of medications, arranging specialist appointments and reviewing endoscopies.’

Crohn’s disease symptoms usually present for the first time in those aged 30 years and younger, while ulcerative colitis mostly occurs in people aged 15–30.

‘A lot of the first steps towards diagnosis should be the domain of a good GP: detailed patient history-taking, examination, relevant pathology tests, and the referral for colonoscopy if IBD is a real possibility,’ Slutzkin said. ‘Emotional support and education is extremely important, especially as first presentation is often in late childhood or teenage years.’

For Moore, educating patients, especially the younger ones, about IBD is one of the most important roles a doctor can play.

‘IBD is quite a hidden disease because the bowels aren’t something people normally want to talk about,’ he said. >>

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*From top:* Dr Andrew Slutzkin believes GPs should be the “cornerstone” of a person’s IBD management; Dr Greg Moore said educating patients about IBD and its symptoms is among a doctor’s most important roles in the management of the disease.

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INFLAMMATORY BOWEL DISEASE

‘It is a condition that primarily affects people between the ages of 15 and 45, in terms of the onset, and these are critical times in terms of establishing peer groups, education and career.’

Taking control

While there is currently no cure for IBD, Moore believes it is important to for people to understand that appropriate and effective management means patients are able to lead normal lives.

‘What I tell my patients is that we don’t know the cause, and we really don’t have a cure to just switch off the trigger, but we are getting really good at controlling the disease and preventing damage,’ he said.

‘This way, our patients are able to go on to lead normal lives and prevent further damage.’

Patient access to appropriate and cost-effective services for IBD remains a challenge, however, with national hospital costs reaching more than $100 million per year.1 Data from the Australian Institute of Health and Welfare (AIHW) has found that hospitalisation for IBD has increased by 49% in the last decade, with more than 27,000 admissions in 2009–10.4

The physical aspects of IBD can also have adverse effects on a person’s life.

‘A lot of IBD patients who are in their school years underperform because they will have significant amount of time off. There is also stress and fatigue because the peak onset is at the teen years and early adulthood,’ Moore said. ‘If we are not able to effectively diagnose and manage these symptoms at an early stage, it is going to escalate to require hospital care and cause further damage.’

A study published in the Journal of Crohn’s and Colitis found people with IBD lose an average of 7.2 days of work per year as a result of associated symptoms.5

‘A lot of time off work is common in the older patients,’ Moore said. ‘We talk about absenteeism, but also *presenteeism*, where they will make it to work but end up underperforming because they are fatigued or need to constantly go to the toilet.’

‘But it is very important to point out that the medical profession has become very good at controlling and preventing further damage in patients.’

IBD-related loss of production also has a significant economic impact.

According to a PricewaterhouseCoopers report commissioned by Crohn’s and Colitis Australia, an estimated $380 million in productivity was lost in Australia in 2012.1

‘It is really a big problem when we lose that much money because people don’t have a proper understanding of the disease and it takes so long to diagnose it,’ Moore said.

‘Increasing knowledge about IBD will not only help those who are suffering from it, it will help the economy as a whole.

‘GPs can play a key role in this area because they can refer when necessary and continue to manage the cases effectively.’

References