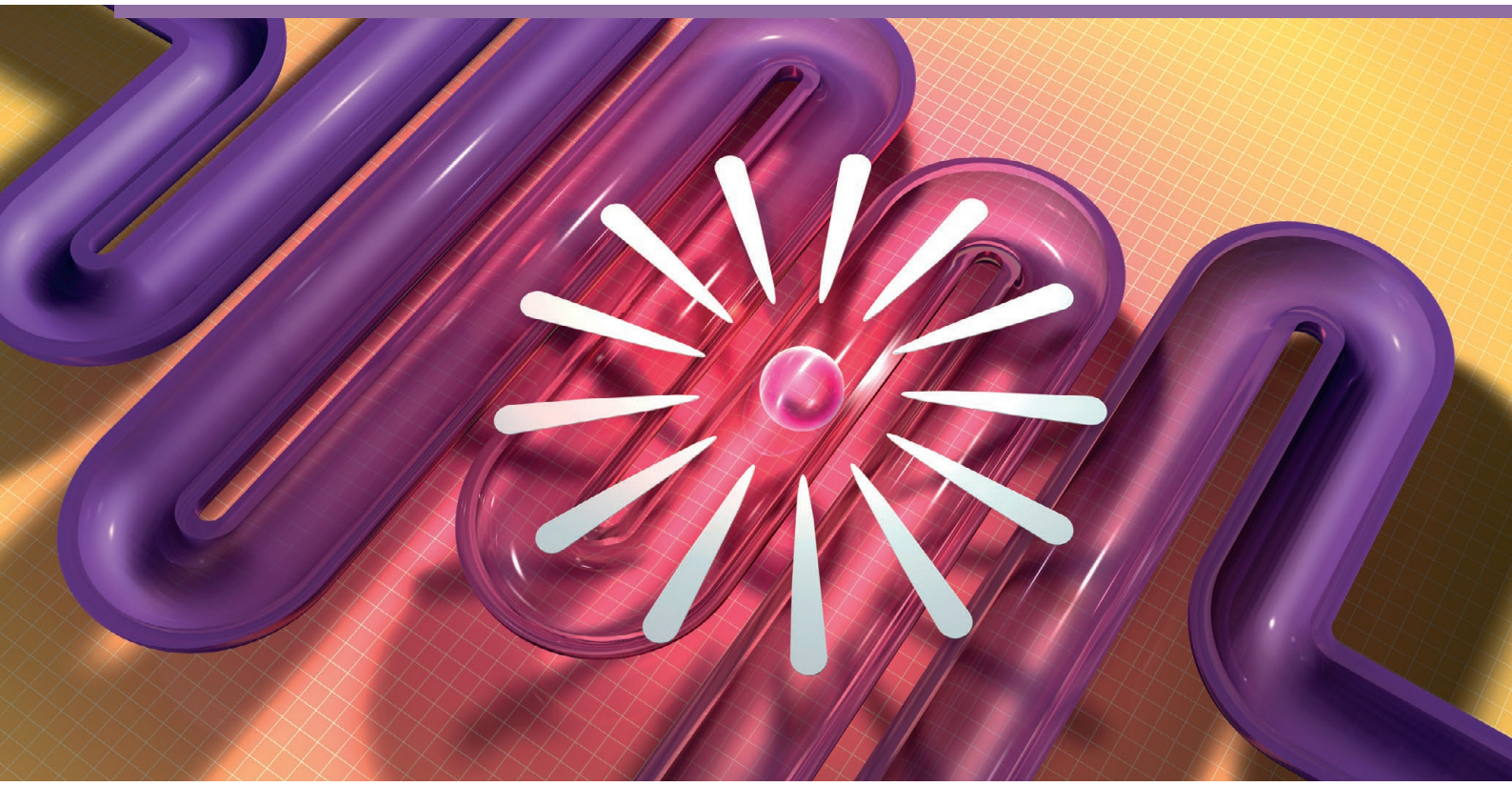

Inflammatory bowel disease – a focus on Crohn's disease and ulcerative colitis

Crohn's disease and ulcerative colitis are the principal forms of chronic inflammatory bowel disease (IBD). Currently over 20,000 people are affected by IBD in New Zealand; approximately the same number as those who have type 1 diabetes. Many people with IBD are diagnosed after years of delay, resulting in worse outcomes. Primary care, therefore, has an important role in early identification of these patients, and in ongoing support after they are diagnosed, including medicines management and detection and treatment of flares. While no "cure" for IBD exists, pharmacological management of symptoms – accompanied by education and self-management strategies – can often support the patient's return to their normal daily activities.

KEY PRACTICE POINTS:

- Crohn's disease and ulcerative colitis are the two main forms of chronic inflammatory bowel disease (IBD); rates of both in New Zealand are amongst the highest in the world and are increasing due to multifactorial reasons
- The initial presentation of the two conditions can be similar, involving both bowel-specific and general symptoms; a definitive diagnosis is made using a combination of clinical, laboratory, endoscopic and histological investigations
- Medicines that can be prescribed initially in primary care for acutely unwell patients include aminosalicylates and corticosteroids, administered either orally or topically
- Patients with suspected IBD should be referred to a gastroenterologist for confirmation of the diagnosis with a colonoscopy and biopsies, and establishment of a tailored treatment regimen. Surgical procedures, or further treatment with immunomodulatory medicines, e.g. azathioprine, or biologic medicines, e.g. adalimumab, may also be required.
- Primary care clinicians have an ongoing role in the care of patients with IBD, including the management of relapse or complications, and monitoring adherence and the adverse effects of medicines
- In addition to pharmacological and surgical interventions, patients should be provided with information to optimally self-manage IBD, and equipped with strategies to cope with associated psychological and emotional effects
- A review by a dietitian is ideally required, particularly in younger patients with IBD

Crohn's disease and ulcerative colitis are chronic inflammatory bowel diseases

Inflammatory bowel disease (IBD) is an umbrella term that encompasses conditions associated with chronic inflammation of the gastrointestinal tract, of which Crohn's disease and ulcerative colitis are the principal forms, with a few cases remaining as "IBD unclassified".[1] Both conditions are characterised by a relapsing and remitting pattern of symptoms, which can vary widely between individuals, and invariably create challenges in the patient's daily routine.[1] Although there are many similarities in their presentation and management, there are significant differences in the gastrointestinal characteristics of the two conditions (see: "Making a diagnosis can be challenging").[1]

The exact cause of IBD remains uncertain

Both Crohn's disease and ulcerative colitis are believed to be triggered by environmental factors in genetically susceptible individuals – although the precise cause of either form of IBD is unknown.[2] More than 200 risk genes have been linked to IBD susceptibility, many of which are shared with other autoimmune conditions and can lead to an overly aggressive immune response.[2] Possible contributing environmental factors have been grouped under the broad concepts of "urbanisation" and a "westernised" lifestyle, including:[2, 3]

Changes to diet, i.e. the abundance and type of food (see: "IBD has become more prevalent over time" and "Diet" in the "Other aspects of management" section); obesity itself is not considered to be a risk factor for IBD development, but excess weight increases the risk of complications in people with established disease, e.g. venous thromboembolism during a flare

Access and utilisation of healthcare, e.g. antibiotic use during childhood has been associated with an increased risk of IBD, however, it is unclear if this is a causal association (specific indications and antibiotic classes have not been consistently reported between prospective investigations)

Changes to the gut microbiota (dysbiosis) – which itself may be a result of dietary change, antibiotic use or travel; for example, decreases in the prevalence of Firmicutes bacteria in the gut, as well as increases in the prevalence of Enterobacteriaceae isolates, are both associated with IBD development

Pollution/allergen exposure (including smoking) and **hygiene practices**

Hygiene practices during the early years of life are thought to be a significant contributor to the risk of developing IBD and other immune-mediated conditions (the "hygiene hypothesis").[2] Specifically, early childhood exposure to particular microorganisms, parasites and allergens is proposed to help establish immune tolerance.[2] In contrast, excessive avoidance of these factors may result in inadequate immune development.[2]

IBD has become more prevalent over time

Since the 1950s there has been a substantial increase in the number of people with IBD worldwide.[2, 4] IBD was initially thought to predominantly affect people of Western European descent, however, an increase in cases is now being observed in countries with differing ethnic distributions that previously had a low incidence of IBD, e.g. in South America, Africa and Asia. This change is likely due to urbanisation and the adoption of more western practices as described previously, e.g. diet, healthcare and hygiene, and is the driver of the net increase in incidence worldwide.[2]

New Zealand has one of the highest rates of IBD in the world; at least 20,000 people are currently estimated to be affected (one in every 227 people), approximately the same as the number of people with type 1 diabetes.[4, 5] However, given that New Zealand has no national IBD registry, timely and accurate data on prevalence is limited. In an 18-year analysis of IBD in the Otago region, 52.1% of cases diagnosed were Crohn's disease, 40.0% were ulcerative colitis and 7.9% were IBD unclassified.[6] The same study found that IBD was substantially less common in people of Māori, Pacific and Asian descent compared with Europeans, who accounted for 97.1% of all diagnoses.[6] Only 1.8% of cases were in people of Māori ethnicity, despite this group accounting for 7.5% of the Otago population.[6] Factors such as genetics, diet, healthcare access and under-diagnosis may explain differences in these ethnic trends.[5]

New Zealand is an example of a "Western" country in which the incidence of IBD continues to rise.[4] Between 2003 and 2013, the number of new IBD cases per year increased by an average of 8.1% overall.[5] Further investigation is required to understand why New Zealand differs from other Western countries where the IBD incidence rate has stabilised, despite seemingly sharing similar cultural, lifestyle, dietary and socioeconomic influences in their societies.

When to suspect IBD

Both Crohn's disease and ulcerative colitis have a peak incidence in people aged between 18 and 35 years, with a second peak of ulcerative colitis between age 60–70 years, although IBD can present in people of any age.[3, 4] Males and females are equally affected, and having a family history of

IBD should increase clinical suspicion, particularly if it involves first-degree relatives as this approximately doubles the lifetime risk.[2, 6]

The characteristic symptoms that patients with IBD present with include (also see Table 1):[1]

- **Diarrhoea** – a common feature in patients with ulcerative colitis and in most cases of Crohn's disease (N.B. people with small intestinal Crohn's disease often do not experience diarrhoea); most people with ulcerative colitis present with diarrhoea containing blood or mucus, however, the stool may be solid if there is inflammation affecting the rectum only.

  Practice point: many clinicians focus on bowel frequency, however, it is important to also ask patients with suspected IBD about the urgency of their motions and whether they have symptoms at night as these are often a more prominent concern and can have a greater impact on their quality of life, e.g. fear of not being able to reach a toilet in time or having to plan activities around toilet access.[7]

- **Other bowel symptoms** – e.g. abdominal pain, faecal incontinence, tenesmus. Less frequently there may be symptoms associated with bowel stricture or obstruction, fistulae and abscesses.
- **Non-bowel symptoms** – e.g. tiredness or malaise, fever and weight loss. Children may present with failure to thrive. Less frequently there may be skin involvement (e.g. erythema nodosum), eye involvement (e.g. episcleritis or iritis), mouth involvement (e.g. aphthous ulcers on the inside of the lips/cheeks/underneath the tongue or angular cheilitis), night sweats or primary sclerosing cholangitis

People with IBD also have an increased prevalence of other conditions associated with immune dysfunction, e.g. asthma, psoriasis, spondylarthritis and other forms of joint disease, type 1 diabetes, autoimmune hepatitis.[8] Therefore, a pre-existing diagnosis of any of these conditions may increase clinical suspicion of IBD in patients with persistent adverse bowel symptoms.

Making a diagnosis can be challenging

Research nationally and internationally shows that there is still a significant delay to diagnosis for patients with IBD.[9] In the past, diagnosis relied primarily on the histological findings from gut tissue biopsies, however, the approach has now shifted to account for multiple aspects, including the clinical presentation, laboratory investigations, endoscopic findings and histology (Table 1).[10]

If IBD is suspected after taking the history, physical examination may then reveal features that support this diagnosis, such as pallor suggestive of anaemia, mouth ulcers, abdominal tenderness, evidence of inflammation or visible anal fistula.[10] The degree of inflammation within the bowel does not always reflect symptom severity, and there is the potential to under- or over-estimate inflammation due to the subjective nature of many of the gastrointestinal symptoms. A combination of laboratory parameters, history and presentation should be used to establish disease severity, rather than relying solely on patient-reported symptoms.

It can sometimes be difficult to make a clear distinction between Crohn's disease and ulcerative colitis as there is overlap between diagnostic features (Table 1).[1] Often only colonoscopy can differentiate the two conditions. In 5–15% of patients with IBD, endoscopic and histological findings cannot distinguish between Crohn's disease and ulcerative colitis (labelled as IBD-unclassified).[1] Irrespective of the classification, IBD treatment is often the same initially, and tailored later in management.

Differential diagnoses should also be considered. Features of both main forms of IBD may overlap with other bowel conditions, including:

- Infectious diarrhoea
- Diverticulitis (more likely in patients aged >60 years)
- Colitis secondary to other causes, e.g. infection, ischaemia (in patients aged >60 years)
- Coeliac disease – usually not bloody diarrhoea
- Irritable bowel syndrome – although diarrhoea is not bloody and symptoms are usually not present at night
- Colorectal cancer

Referring patients with suspected IBD

If a diagnosis of IBD is likely then a gastroenterology assessment is required. While awaiting the appointment, medicines for symptomatic relief can be initiated immediately in primary care (see: "Medicines used in the treatment of IBD"). If needed, seek gastroenterology advice to guide medicine selection. During this time, patients should also receive education about IBD and lifestyle changes they can make (see: "Lifestyle advice for patients with IBD").

Urgent referral. In general, urgent referral to secondary care should be considered if the patient has any of the following symptoms:*

- Nocturnal symptoms, e.g. abdominal pain and diarrhoea, causing the patient to wake at night for > 2 weeks (functional diarrhoea such as irritable bowel syndrome usually stops at night)

Table 1. Distinguishing features and laboratory investigations for diagnosing IBD.[10, 11]

	Crohn's disease	Ulcerative colitis
Clinical presentation		
Diarrhoea with urgency	Frequently	Frequently
Rectal bleeding	Occasionally	Frequently
Mucus defecation	Occasionally	Frequently
Abdominal pain	Frequently	Occasionally
Abdominal mass	Sometimes in right lower quadrant	Rarely
Fever	Frequently	Uncommon (seen in severe disease)
Fatigue	Frequently (50% at the time of diagnosis; more common later in disease)	Frequently
Perianal disease	Yes	No
Endoscopic features		
Location	Can affect any part of the GI tract (but less commonly the rectum)	Always affects the rectum; extends into the colon to varying degrees
Inflammation/ ulceration	Involves deep geographic and serpiginous (snake-like) ulcers; often "patchy" transmural inflammation	Involves continuous superficial ulcers (limited to the mucosa); there is a sharp transition between diseased/ normal colon tissue
Stricture/fistulas	Yes	No
Histological features		
Fat wrapping (adipose tissue expands towards antimesenteric surface)	Frequently	Rarely
Granulomas	Occasionally	Rarely
Lymphoid aggregates	Frequently	Rarely
Crypt abscesses	Uncommon	Frequently
Patchiness	Frequently	Uncommon

Recommended laboratory investigations		
Full blood count	To detect anaemia (usually microcytic) or signs of infection (leucocytosis) or inflammation (thrombocytosis).	
C-reactive protein (CRP)	CRP will often, but not always, be raised in active IBD; CRP may correspond to severity in people with Crohn's disease but can be more variable in people with ulcerative colitis. CRP may not be raised in left-sided ulcerative colitis.	
Electrolytes	Can be important especially if diarrhoea is prominent.	
Renal function	Useful as a baseline prior to initiation of medicines.	
Liver function	Liver and bile duct abnormalities may be present in some patients with IBD. Albumin can be an important marker of malnutrition and protein-losing enteropathy.	
Stool culture	To help exclude an infectious cause of diarrhoea (including *Clostridium difficile*).	
Additional laboratory investigations to consider		
		When to consider
Faecal calprotectin	A neutrophil-derived protein regarded as the most sensitive marker of inflammation in people with IBD. Levels of faecal calprotectin often reflect disease activity but not the cause of inflammation. IBD is very unlikely if levels are <50 micrograms/g and it is considered a strong negative test for IBD. As levels of faecal calprotectin rise above 50 micrograms/g, so does the likelihood of IBD. A gastroenterologist would generally consider a level of ≥150 micrograms/g to be supportive of an IBD diagnosis; in some people, levels can be in the thousands.	■ Can be useful to support a diagnosis in some cases, however, it is costly and therefore needs to be requested appropriately ■ Strongly consider if the patient's history is consistent with IBD and a colonoscopy is not being undertaken – or the results are inconclusive – and infection/NSAID use have been excluded
Coeliac screen	Tissue transglutaminase IgA (tTG IgA) antibodies are present in nearly all people with active coeliac disease (except those with IgA deficiency).	If coeliac disease is also suspected as a differential diagnosis, e.g. symptoms align with IBD, but the patient has a family member with coeliac disease. N.B. coeliac disease does not cause bloody diarrhoea.
Thyroid stimulating hormone	Thyroid disturbances may concomitantly exist in some patients with IBD (or coeliac disease), or be an alternative explanation in patients with fatigue and bowel symptoms (thyroid dysfunction can increase intestinal motility, e.g. Graves' disease).	If features consistent with thyroid disfunction are prominent in patients with bowel symptoms, e.g. fatigue, or if coeliac disease is suspected (thyroid dysfunction occurs more frequently in patients with coeliac disease).

Urgent referral (continued)

- Severe abdominal pain or severe diarrhoea (greater than eight times a day), with or without bleeding
- Unintentional weight loss (>4.5 kg), persisting longer than four weeks
- Fever, tachycardia, hypotension, dehydration, night sweats or other symptoms of severe systemic illness alongside frequent bowel motions

These features may be indicative of complications including infection, malabsorption, strictures, obstruction, abscesses, fistulae, bleeding, perforation, and rarely toxic megacolon.

* Specific urgent referral criteria may differ across New Zealand. Refer to your local Health Pathways for region-specific guidance.

The management of IBD

Once a definitive diagnosis is reached, management can then be individualised depending on the type and severity of IBD. Traditionally, the goal of treatment has been to achieve symptomatic remission. However, the treatment target has now shifted towards the concept of "deep remission", where asymptomatic status is supported by evidence of endoscopic healing or laboratory markers.[12] Recently, faecal calprotectin has been identified as potentially a superior marker of remission in some patients compared with clinical or serum parameters, as it tends to correlate well with endoscopic and histological findings, and levels may increase in the weeks leading up to a flare.[12] However, if faecal calprotectin is not initially found to correlate with these factors, alternative markers need to be used.

IBD management includes both pharmacological and surgical interventions and colonoscopic surveillance, under the guidance of a gastroenterologist. However, given the chronic nature of IBD, primary care clinicians will continue to be involved in:

- Initial management of relapses
- Recognising and treating complications (or referring if severe)
- Reviewing and renewing prescriptions, including adherence
- Monitoring for adverse effects of treatment, e.g. three-monthly blood tests for patients on azathioprine
- Providing education and support, such as encouraging the use of Crohn's and Colitis New Zealand resources

N.B. Most DHBs have IBD nurse specialists to provide patient support, advice and follow up. Some patients may be able to communicate with their IBD healthcare team using IBDsmart, a smartphone application.

For more information on IBDsmart, see: **https://www.guthealthnetwork.com/tools-and-links/ibdsmart/**

Medicines used in the treatment of IBD

There are four main groups of medicines that are used in the treatment of IBD: aminosalicylates, corticosteroids, immunomodulatory medicines and biologics (Table 2). Selection will vary based on the type and severity of presentation, as well as patient-specific characteristics and co-morbidities. Antibiotics may also have a short-term role when inducing remission, e.g. metronidazole, but these generally are only used in patients with clear evidence of infection, e.g. abscesses in conjunction with incision and drainage or perianal fistulising disease.

Medicines for IBD are often taken orally, however, some patients with mild-to-moderate IBD limited to the rectum can also use either enema or suppository formulations of aminosalicylates such as mesalazine, or corticosteroids, e.g. hydrocortisone acetate, to deliver high concentrations directly to the inflamed mucosa.

Monitoring requirements. High medicine doses are initially used to control acute exacerbations of IBD symptoms. Once control has been achieved, the dose is reduced to balance the risk of additional flares with medicine-specific adverse effects that may occur (Table 2). As such, primary care has an important role in proactively monitoring for these adverse effects, checking the patient's adherence to their medicines and helping co-ordinate decisions around treatment escalation and de-escalation.[18]

For more information on monitoring requirements in patients with IBD treated with immunomodulatory or biologic medicines, see: **https://www.nzma.org.nz/journal-articles/new-zealand-society-of-gastroenterology-guidelines-on-therapeutic-drug-monitoring-in-inflammatory-bowel-disease**

Funded access to biologics for IBD in New Zealand remains limited. As of December, 2020, two biologics are currently funded in New Zealand for patients with severe IBD (adalimumab and infliximab).[17] Approximately two-thirds of patients who take a biologic will have a primary response to treatment, however, those who do not experience a response or have a later relapse often need to trial alternatives.[19] Internationally, ustekinumab or vedolizumab are often used as a first-line biologic for treating patients who are biologic-naïve or who have not achieved an adequate response with standard treatment. Of these two medicines, only ustekinumab is an approved medicine in New Zealand for moderate to severe Crohn's disease, but it is not funded.[1, 20] See "2026 funding update" box, Page 12.

Table 2. Fully funded medicines used in the treatment of patients with IBD.[1, 17]

<table>
<tr><th colspan="2">Group</th><th colspan="4">Medicine</th><th>Notes</th></tr>
<tr><td rowspan="6">Can be initiated in primary care</td><td rowspan="5">Aminosalicylates (ASAs)</td><td colspan="4">Mesalazine</td><td rowspan="5">• Often used first-line for the treatment of mild-to-moderate IBD (predominantly for ulcerative colitis as ASAs are much less effective in Crohn's disease)
• Oral use is the most common; topical formulations of mesalazine (either enema [for left-sided disease] or suppositories [for rectal disease]) are also available for patients with mild-to-moderate disease – this can be provided in combination with oral use
• Gastroenterologists may advise initiating an ASA (or a corticosteroid) while awaiting an assessment if IBD is likely and the patient has severe symptoms
• ASAs increase the risk of blood dyscrasias
• Patients should be advised to report any unexplained bleeding, bruising, fever, malaise, purpura, or sore throat, in addition to monitoring for medicine-specific adverse effects</td></tr>
<tr><td>Brand</td><td>Oral</td><td>Suppository</td><td>Enema</td></tr>
<tr><td>Asacol</td><td>Acute flare: 0.8–1.6 g three times daily
Maintenance: 400–800 mg three times daily</td><td>0.5–1 g up to 3 times daily, reduce dose according to response; max 1 g twice daily if using in addition to oral therapy</td><td>Not available</td></tr>
<tr><td>Pentasa</td><td>Acute flare: up to 4 g once daily or in divided doses
Maintenance: 2 g once daily</td><td>1 g 1–2 times daily</td><td>1 g at night for 2–3 weeks</td></tr>
<tr><td colspan="4">Olsalazine (oral) – rarely used
• Acute flare: initially 500 mg the first day, increased by 500 mg daily up to 2g daily in divided doses; maximum 1 g three times daily
• Maintenance: 500 mg twice daily</td></tr>
<tr><td colspan="4">Sulfasalazine (oral) – mainly used to treat accompanying joint pain
• Acute flare: 1–2 g four times daily
• Maintenance: 500 mg four times daily</td></tr>
<tr><td>Corticosteroids</td><td colspan="4">Prednisone (oral)
• Acute flare: initially 40 mg daily for at least two weeks, then reduce dose by 5 mg per week

Hydrocortisone acetate (enema)
• 1 metered application (approximately 90–100 mg) inserted into the rectum 1–2 times daily for 2–3 weeks, then once daily on alternate days</td><td>• Prescribed for acute treatment if an ASA is ineffective at controlling symptoms, or sometimes used initially in patients with severe symptoms
• Commonly used initially for patients with diffuse Crohn's disease or left-sided colonic disease
• Not indicated for IBD maintenance treatment (avoid long-term use)
• Monitor risk of osteoporosis and osteonecrosis with oral corticosteroid use</td></tr>
<tr><td rowspan="4">Initiated by a gastroenterologist as required</td><td rowspan="2">Immuno-modulators*</td><td colspan="4">Azathioprine (commonly used)
• 2.5mg/kg body weight daily

Mercaptopurine
• 1–1.5 mg/kg body weight daily</td><td>• Can be used in pregnancy
• May take 3–6 months to achieve remission
• Serum thiopurine methyltransferase (TPMT) needs to be requested first to identify patients at risk of serious adverse effects and to assess how much azathioprine and mercaptopurine to prescribe
• Three-monthly blood tests are required (initially weekly)</td></tr>
<tr><td colspan="4">Methotrexate
• 15–25 mg together with folic acid 5 mg, once weekly</td><td>• Second-line immunomodulator
• Not suitable in pregnancy due to teratogenic effects</td></tr>
<tr><td rowspan="2">Biologics*</td><td colspan="4">Adalimumab (subcutaneous injection)
• Maintenance 40 mg, every two weeks

Infliximab (intravenous)
• Maintenance 5mg/kg body weight, every 8 weeks</td><td>• Initial application for Special Authority (SA) for adalimumab is by a gastroenterologist or practitioner on the recommendation of a gastroenterologist
• Do not give live vaccines when using a biologic; administer these at least one month before initiation
• Consider annual influenza vaccine and five-yearly pneumococcal vaccine</td></tr>
</table>

* **2026 funding update:** The biologics, ustekinumab and vedolizumab, and upadacitinib, a Janus-kinase inhibitor (type of immunomodulator) are now funded with Special Authority approval. Refer to the NZF for information on dosing and other prescribing considerations for these medicines.

Lifestyle advice for patients with IBD

Following diagnosis, primary care has a pivotal role in educating patients about IBD and directing them to resources that may help them better self-manage their condition. Lifestyle changes alone are insufficient to completely control IBD activity but can help reduce the frequency and severity of flares when accompanied by appropriate medicine use (see: "Medicines used in the treatment of IBD").

Smoking cessation. All patients with IBD who smoke should be advised to stop.[1] In patients with Crohn's disease, smoking is associated with worse disease outcomes and they are approximately 30% more likely to require surgery than non-smokers.[13]

Practice point: patients with ulcerative colitis should be advised that smoking cessation sometimes precipitates a flare of disease activity, however, it is important to focus on the broader long-term health benefits of smoking cessation, e.g. a reduced cardiovascular disease risk.

Diet. There is conflicting evidence regarding the role of diet in both ulcerative colitis and Crohn's disease; to date, no single dietary component has been linked to symptom relapse.[14] If a dietary trigger is suspected, however, it is reasonable for the patient to trial avoidance to see if symptoms improve. Patients with IBD should be encouraged to maintain a healthy overall diet, with the International Organisation for the Study of Inflammatory Bowel Diseases now recommending the following emphases:[14]

- **Crohn's disease** – ensure a regular intake of fruits and vegetables (in the absence of symptomatic strictures)
  - **Reduce:** the intake of saturated/trans fats, foods with high levels of emulsifiers, highly processed dairy or foods rich in maltodextrins (e.g. salad dressings, canned soups, sports drinks), foods with high levels of artificial sweeteners
  - **Avoid:** unpasteurised dairy products where possible
- **Ulcerative colitis** – increase consumption of natural sources of omega-3 fatty acids such as salmon or flax/chia seeds
  - **Reduce/avoid:** same foods as for Crohn's disease, as well as potentially avoiding red and processed meat

In addition, if a patient with IBD is overweight, or gains weight as a result of steroid-use, then weight loss should be encouraged to reduce the risk of complications.[3]

Dietitian review should be strongly considered in all patients with IBD, particularly in younger patients as they often restrict their diet excessively in an attempt to control symptoms, leading to malnourishment. Patients with IBD can be referred for publicly funded dietitian support if they experience unintentional weight loss and/or nutrient deficiencies as evidenced by diet history and/or blood tests, e.g. low iron stores, vitamin B12, folate. One technique utilised by dieticians is called Exclusive Enteral Nutrition (EEN), which has been found to be as effective as corticosteroids in inducing remission in children with Crohn's disease (and to a certain extent in adults).[15]

For more information on EEN, see Appendix 4 in **https://media.starship.org.nz/inflammatory-bowel-disease-appendices/Appendices_Aug_2015.pdf.**

Exercise. Studies have demonstrated that weight-bearing exercise can help reduce fatigue in patients with IBD, and may potentially help decrease disease activity.[1, 16] In addition, exercise improves bone health, decreasing the risk of osteoporosis, e.g. in patients taking prolonged courses of corticosteroids.[1]

Psychological coping skills. Depression and anxiety are more common in people with IBD, and while stress itself is not considered a cause of IBD, it can exacerbate symptoms when they do occur.[1] Patients should be equipped with cognitive and behavioural strategies to minimise the impact of IBD on their daily life, and it is important to investigate whether they have emotional support networks in place, e.g. family, friends, community support groups.[1] Although patients are encouraged to accept that they have a chronic incurable illness, it should be emphasised that IBD does not have to dominate their life, and that there are ways to control/minimise stress, and to effectively manage IBD during their normal daily activities and employment.

Practice point: patients often only talk about the impact IBD symptoms have on their life when directly asked. Ask questions early on to initiate a broader discussion around IBD, e.g. "*Has this condition affected your ability to engage in activities you normally enjoy?*"

2026 funding update

The biologics, ustekinumab and vedolizumab (injections), are both now approved medicines and funded with Special Authority in New Zealand for some patients with moderate to severe Crohn's disease or ulcerative colitis. Upadacitinib (oral), a Janus-kinase inhibitor, is also approved and funded for some patients. Janus-kinase inhibitors are a type of immunomodulator. Special Authority applications for these medicines can be made by any relevant practitioner, but they are usually initiated in a secondary care setting.

For general information about upadacitinib, see: **bpac.org.nz/2025/atopic-dermatitis.aspx** *(this article focuses on the use of upadacitinib for treatment resistant atopic dermatitis; general information about the medicine may still be relevant)*

Surgical management of IBD

Despite optimal medicine use, approximately 60–80% of people with Crohn's disease require a segmental intestinal resection, and 20% of those with ulcerative colitis undergo proctocolectomy for medically refractory disease.[19] The need for surgery, and the type of procedure required, will primarily be directed by the gastroenterologist and colorectal surgeon, but decisions will be informed by evidence from monitoring in primary care.

Indications for surgery in patients with IBD:

- Lack of response or intolerance to standard funded medicines
- Pre-cancerous or cancerous changes in the colon in people with a long history of active IBD (see: "surveillance colonoscopy")
- Crohn's disease – complications such as fistulae, abscesses, perforation, excessive bleeding or stricture leading to obstruction
- Ulcerative colitis – acute complications, e.g. toxic megacolon or haemorrhage

Patients taking a corticosteroid, immunomodulator or biologic medicine prior to surgery have a higher post-operative risk of infection.[15] Therefore, steps should be taken to alleviate infection risk, e.g. pre-operative antibiotics and advising weight loss and smoking cessation if relevant.[19]

Other longer-term aspects of management to consider

Surveillance colonoscopy. Patients with IBD have an increased risk of developing bowel cancer compared with the general population.[21] The mortality rate due to bowel cancer in people with IBD is 10–15%. Therefore, surveillance colonoscopy should be performed after IBD symptoms have been present for eight to ten years, and then repeated every:[21]

- 5 years for patients with a low risk of bowel cancer
- 3 years for patients with an intermediate risk of bowel cancer
- 1 year for patients with a high risk of bowel cancer

N.B. The risk calculation depends on duration and extent of disease, and the severity of inflammation and can change after every colonoscopy.

For more information on bowel cancer risk determinants in patients with IBD, see: **https://www.health.govt.nz/system/files/documents/publications/colorectal-cancer-surveillance-guidance.pdf**

IBD can affect medicine absorption. Changes to the characteristics and composition of the GI tract varies between patients with IBD.[1] In some cases, IBD pathology may substantially influence the transit, absorption and subsequent bioavailability of oral medicines, including those used to treat IBD itself, and those required for managing co-morbidities.[1] In patients with IBD that exhibit a sub-optimal response to oral medicines without an obvious explanation, consult with a pharmacist or gastroenterologist for advice.

Contraception. IBD may influence the suitability of some hormonal contraceptives:[22]

- IBD increases the risk of osteoporosis, and the effect of depot medroxyprogesterone acetate on bone density may be additive. Therefore, an alternative contraceptive that does not affect bone density should be advised.
- The combined oral contraceptive pill (COC) may not absorb as effectively in patients with Crohn's disease with small bowel involvement; avoid COC in patients prone to severe exacerbations requiring hospitalisation

Pregnancy. For women wanting to become pregnant, maintaining optimal control over IBD symptoms generally increases the likelihood of conception, particularly in people with Crohn's disease. Patients should be advised that IBD is associated with a higher risk of pre-term birth and caesarean sections are more common in patients with active disease.[22] Most medicines used for IBD can be safely continued during pregnancy:[1, 23]

- The main exception is methotrexate, which is contraindicated in pregnant women (Table 2); pregnancy should be delayed for at least three to six months after stopping methotrexate
- Biologics such as infliximab and adalimumab can cross the placenta during the first trimester of pregnancy; while these medicines are not thought to harm the fetus, live vaccines are routinely avoided in the infant during the first six months of life if the mother receives biologic treatment due to risk of immunosuppression (however, the evidence regarding this is conflicting)

Prognosis is variable

Both principal forms of IBD have a relapsing-remitting course; the long-term prognosis varies considerably and is dependent on patient characteristics and their tailored treatment plan.

Ulcerative colitis:[24]

- Following diagnosis, approximately 50% of patients experience a flare during the next one to two years
- A small proportion have a single presentation of symptoms followed by no recurrence or perhaps a single flare over the course of decades
- Approximately 1% of patients with ulcerative colitis experience persistently active disease five years after diagnosis

Crohn's disease:[25]

- The course of disease tends to be more variable and less favourable than for ulcerative colitis – prognosis varies based on anatomical location and severity
- Following diagnosis, cumulative relapse rates have been demonstrated to be:
  - 53% at one year
  - 85% at five years
  - 90% at ten years
- Patients requiring systemic steroid treatment for their first flare, or that present with perianal involvement, are more likely to experience a relapse of symptoms later

If surgery is required for either form of IBD, then a colonoscopy after one year – accompanied by visualisation of the surgical anastomosis – can give a more definitive and individualised prognostic outlook.

Leading a fulfilling life with IBD

Although each patient's experience is unique, it is possible to live a fulfilling and productive life despite being diagnosed with IBD, and this should always be a focus in early discussions about the condition.

Crohn's and Colitis New Zealand has prepared a "Living with IBD Handbook", which is a useful resource to enable patients to think positively about their future and identify ways with which they can better self-manage their condition. IBD Passport provides information relating to travel with IBD and is endorsed by the New Zealand Society of Gastroenterology and Crohn's and Colitis New Zealand.

For access to the "Living with IBD Handbook", see: **https://crohnsandcolitis.org.nz/IBD+Handbook**

For access to the "IBD Passport", see: **https://www.ibdpassport.com/**

This article is available online at: **www.bpac.org.nz/2021/ibd.aspx**

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