



BETTER CARE, BETTER LIVES:

Crohn's & Colitis UK 2026 Manifesto for Scotland

**CROHN'S &
COLITIS UK**

ABOUT CROHN'S AND COLITIS

More than 50,000 or 1 in 103 people in Scotland are living with Crohn's Disease and Ulcerative Colitis, the two main forms of Inflammatory Bowel Disease (IBD). This is nearly double previous estimates, making Scotland the UK's highest prevalence nation for IBD.

These lifelong diseases are painful, debilitating, rarely known and widely misunderstood. They can affect almost every part of the body and every aspect of life: from digestion and joints to energy levels, mental health, education, and work.

There is no known cure.

The burden of Crohn's and Colitis on the NHS is increasing year on year, and, per patient, costs are comparable to cancer and heart disease.

Yet inadequate resources and sustained underfunding are already leaving thousands of people without timely, effective treatment. This is driving preventable complications, avoidable hospital admissions and emergency surgery; pressures that are entirely predictable and, with the right investment and planning, avoidable. With case numbers continuing to rise, these challenges will only intensify, placing increasing strain on NHS Scotland and limiting its ability to deliver safe and sustainable care.

Addressing this now is essential to protect patients, reduce avoidable costs, and strengthen the resilience of Scotland's health service over the next Parliament.

HERE'S HOW...

DIAGNOSED IN WEEKS, NOT YEARS

Diagnosis of Crohn's or Colitis is taking years, when it should take weeks.

Every delay comes at a cost. It forces people to live in pain, disrupts work and life, and leads to complications and emergency surgeries that should have been prevented. **People who wait the longest are four times more likely to develop severe bowel complications and twice as likely to require surgery.**

Four in five people suffer through debilitating symptoms for over a month before getting any medical advice. Even then, over three in five wait more than four weeks for a hospital referral, and one in six waits over a year.

WHAT MUST CHANGE

Scottish Government and NHS leaders should:



Awareness raising campaigns:

Partner with charities to raise awareness of the symptoms and reduce delays caused by patients not recognising the signs. High-profile public health campaigns to raise awareness of the seriousness of IBD and its symptoms, such as the Crohn's & Colitis UK initiative '[Cut the Crap](#)' and the [Scottish IBD 'awareness campaign'](#), should be a priority for the Scottish Government to invest in, with support from dedicated experts and a focus on tackling inequalities in diagnosis.



Implement a primary care diagnostic pathway for lower gastrointestinal (GI) symptoms to streamline diagnosis:

The '[National Primary Care Diagnostic Pathway for Lower GI Symptoms](#)' should be implemented across all Health Boards with access to screening tests such as Faecal Calprotectin ensured across all primary care practices to facilitate appropriate and timely referrals.



Unblock the bottleneck in endoscopy:

Ensure endoscopy policy and funding recognises the essential role it plays in the diagnosis of non-cancerous conditions such as Inflammatory Bowel Disease. Introduce ring-fenced endoscopy lists for suspected IBD, train staff, expand capacity, and cut waits.

NOT JUST SEEN, SEEN BY A SPECIALIST

Crohn's and Colitis are unpredictable long-term conditions.

Effective care requires a skilled multidisciplinary team, and rapid access to specialist advice to support people to live well.

Yet IBD services are stretched to breaking point. No service in Scotland meets the IBD standards for staffing.

Many GPs lack the confidence to manage patients during an IBD flare and, as non specialists, cannot provide the level of support offered by IBD nurse specialists — often described by patients as their "lifeline". Yet one in three IBD services in Scotland are failing to meet safe staffing levels for specialist nurses, undermining patient outcomes and putting lives at risk.

People with IBD in Scotland are also struggling to access essential psychological and nutritional support. Complex dietary needs and the gut-brain connection make timely specialist care essential to stop the cycle of worsening mental health and recurrent flares. Despite this, no adult IBD service in Scotland has a psychologist as part of its multidisciplinary team, and only roughly one in ten can offer dietetic support.

WHAT MUST CHANGE

Scottish Government and NHS leaders should:



Introduce a national specialist nursing plan, embedded within the Long Term Conditions Framework, to secure the future of specialist nurses including the IBD nursing workforce. This would include the introduction of recruitment and retention incentives and deliver guidance on training and professional development. IBD Nurse Specialists deliver expert, often life saving care, but services are currently unable to meet demand. National workforce planning is needed to ensure all services meet IBD standards and guarantee that patients receive the specialist support they depend on.



Improve access to specialist psychological and dietetic support that meets the IBD Standards and the needs of people with Crohn's and Colitis. Targeted, ringfenced investment should be allocated to ensure every IBD service can provide embedded psychological and nutritional support. This should be complemented by strengthened referral routes into mental health services and a commitment to promoting effective self-management tools to relieve pressure on the NHS.

ACCESS TO PUBLIC TOILETS SHOULDN'T BE A LUXURY

Access to public toilets is crucial for managing day to day life with Crohn's or Colitis. People living with Crohn's or Colitis often suffer from an unpredictable and urgent need to use a toilet and nine in ten plan their activities around toilet access.

Declining public toilet provision in Scotland has fuelled isolation, anxiety and exclusion, preventing people from going out, working, and taking part in everyday life. One in three people living with Crohn's and Colitis avoid using public transport all the time because they are afraid that they might not make it to a toilet in time.

WHAT MUST CHANGE

Scottish Government should work with local government, businesses and transport providers to:



Improve access to toilets by legislating to introduce a new statutory duty for local authorities to provide a sufficient supply of well-maintained publicly available toilets in their area. This should include reliable information on where toilets are located so people can plan ahead, 'Not Every Disability is Visible' signage and recognition of 'Can't Wait Cards', so that people with Crohn's and Colitis are able to access toilets without fear of stigma or abuse.



Embed accessible toilets as a design principle in all new infrastructure projects to ensure accessible toilets are always considered when building to increase provision for people living with Crohn's and Colitis who rely on access to toilets to be able to leave their home.

GET IN TOUCH

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