

BETTER DIAGNOSIS, BETTER CARE, BETTER LIVES:

Transforming understanding of Crohn's and Colitis in Wales

**CROHN'S &
COLITIS UK**

ABOUT CROHN'S AND COLITIS

Crohn's and Colitis each cause inflammation in the gut and cause a wide range of painful and exhausting symptoms including blood in poo, severe stomach pain, overwhelming fatigue and frequent, urgent diarrhoea. For many people, these symptoms come and go, making life unpredictable and planning near impossible.

Over 26,000 – 1 in 120 – people in Wales live with Crohn's or Colitis. The impact on the NHS is increasing year on year. The cost of care for someone with Crohn's or Colitis is now comparable to cancer and heart disease.

Yet inadequate resources and underfunded health services means thousands of people may go without the treatment they need, leading to serious complications, avoidable hospital admissions and emergency surgery.

DIAGNOSED IN WEEKS, NOT YEARS

Diagnosis should take weeks, yet too many people spend years in a maze of delays, misdirection and dead ends.

Every delay has a cost. It puts people's lives on hold, leaves people in pain and can lead to severe complications and unnecessary emergency surgeries.

One in three wait over a year with debilitating symptoms to see a healthcare professional and one in five waited over six months from referral to diagnosis.

WHAT MUST CHANGE

Welsh Government and NHS leaders should:



Raise awareness early:

Partner with charities to raise awareness of symptoms and reduce delays caused by patients not recognising the signs: This should include public health campaigns, and bring together intelligence for symptom checkers, including on the ways in which people talk about stigmatised and taboo symptoms.



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 Crohn's and Colitis. Introduce ring-fenced endoscopy lists for suspected Crohn's or Colitis, train staff, expand capacity and cut waits.

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NOT JUST SEEN, SEEN BY A SPECIALIST

Crohn's and Colitis are complex and unpredictable long-term conditions. In Wales, over a quarter of adults living with the conditions have endured three or more painful relapses in the past year.

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

Yet Inflammatory Bowel Disease (IBD) services are stretched to breaking point. No service in Wales meets the IBD Standards for staffing.

Many GPs lack the confidence to manage patients in a flare. Too many patients are faced with a lack of communication, chasing for answers and without support.

WHAT MUST CHANGE

Welsh Government and NHS leaders should:



Develop a long-term workforce plan for IBD, supporting services to achieve the IBD Standards on staffing for all members of the multidisciplinary team, and deliver high-quality effective care for patients at all stages of their journey.



Provide targeted funding to **recruit, retain, and train more IBD Nurse Specialists**, ensuring all services meet the recommended staffing levels, prioritising areas with the greatest need. This is essential to improve communication with patients and co-ordination of care, access to expert care, reduce waiting times and prevent avoidable hospital admissions.



Improve access to specialist psychological and dietetic support that meets the needs of people living with long-term conditions to support people with Crohn's or Colitis to live well.

IMPROVE ACCESS TO TOILETS

The lack of and increasing shortfalls in public toilet provision in Wales fuels isolation, anxiety, and exclusion, stopping people from going out, working, or taking part in everyday life. One in three people living with Crohn's or Colitis avoid using public transport all the time because they are afraid that they might not make it to a toilet in time.

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

Improve access to toilets,

including reliable information so people can plan, and 'Not Every Disability is Visible' signage and recognition of 'Can't Wait Cards', so that people with Crohn's or Colitis are able to access toilets without fear of stigma or abuse.



GET IN TOUCH

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