Research reveals 60% of people living with Inflammatory Bowel Disease face financial difficulty (https://www.activelink.ie/node/115828)

New research reveals 60% of people living with Inflammatory Bowel Disease face financial difficulty as a result of their condition

- Patients spend an average of €3,264 annually on managing their IBD including treatment and dietary needs
- Nearly half (47%) have avoided seeking necessary medical care due to cost

60% of people living with Inflammatory Bowel Disease (IBD) in Ireland face financial difficulty as a result of the disease, according to a new report published.

<u>Read the Full Report Here</u> (https://testiscc.sharepoint.com/:b:/g/EeFZZWuVAJZBkuX7Ab_i7v4BnGFjZVdkiKphnvhJugNcQ?e=DMRqMq)

Concerningly, because of costs involved with accessing medical treatment, 47% of people have avoided seeking necessary medical care. The 'Uncovering the Hidden Cost of Crohn's and Colitis' report was launched by Crohn's and Colitis Ireland (CCI), in partnership with Johnson & Johnson Ireland, and reveals the significant financial toll this condition has on the IBD community in Ireland.

IBD, a group of chronic digestive conditions including Crohn's disease and ulcerative colitis (UC), affects an estimated 40,000 people in Ireland. While IBD can be diagnosed at any age, it commonly presents in young adults between 15 and 35, with a notable second wave of diagnoses occurring between 50 and 60. Common symptoms associated with IBD such as diarrhoea, abdominal pain, fatigue, and weight loss can significantly impact a person's daily life.

The report provides insight into the financial challenges faced by people living with IBD in Ireland and identifies the key areas of improvement in IBD care. The findings revealed that direct medical costs are the most significant financial challenge for people with IBD. People living with the incurable condition spend approximately €3,264 annually to manage their disease, which includes treatment and dietary needs. On average, this cohort spends a minimum of 33 hours a year accessing healthcare service,s including travelling to and attending appointments.

Indirect costs also significantly impact patients' overall financial stability.

62% reported that taking time off work due to their IBD has negatively affected their financial situation to some or great extent.

82% of respondents said that they missed work or lost wages as a result of their condition.

Costs associated with attending medical appointments also play a significant role in financial burden with 85% citing mileage and travel costs, 83% citing parking fees, 62% citing overnight stays for medical appointments and 49% citing childcare fees.

Amy Kelly, Chief Operations Officer at Crohn's and Colitis Ireland said "These findings show the true extent of the challenges faced when diagnosed with IBD including the financial burden inflicted. However, it's not just about medical bills, it's about lost wages, dietary adjustments and the constant struggle to access the care people living with IBD desperately need. We urge the government to listen to the needs of the IBD community and improve access to care by including IBD in the Chronic Disease Management Programme and expanding medical card eligibility, ensuring equitable access to essential medical care. This inclusion would provide free, structured care, potentially reducing patients' out-of-pocket healthcare expenses through fewer emergency room visits, hospital admissions, and lower medication costs ."

While the majority of people living with IBD have qualified for the Drugs Payment Scheme (74%), accessing broader support remains a challenge. 39% expressed difficulty in seeing a GP, and qualifying for a medical card or GP visit card is proving to be much more difficult. Only 29% of people with IBD have a medical card and only 13% have qualified for a GP visit card, frequently denied due to IBD not automatically meeting the eligibility criteria. An overwhelming 98% believe IBD should automatically qualify individuals for additional support, underscoring the urgent need for policy reform.

Painting an even more concerning picture is that over a quarter of respondents (26%) reported delaying taking their IBD medication to make it last longer due to the costs involved.

Dr. Orlaith Kelly, Consultant Gastroenterologist, Connolly Hospital, Dublin, said "It's deeply concerning that this report reveals so many people are delaying or skipping essential IBD treatment due to cost, as this negatively impacts how they manage their IBD.

As a consultant gastroenterologist, I see firsthand the immense challenges people living with IBD face, not only with their health but also with the financial and emotional burden of managing their condition. This research underscores the urgent need for a more comprehensive approach to IBD care in Ireland, one that ensures financial barriers do not prevent patients from receiving the treatment they desperately need to manage their condition effectively."

Michaela Hagenhofer, General Manager, Commercial Operations at Johnson & Johnson said. "This report lays bare the reality of the impact IBD can have on a person's overall quality of life and provides a critical insight into the supports needed to improve their well-being. It's vital that the voices of the IBD community are heard and acted upon to ensure that care and support are tailored to their specific needs. We're committed to supporting CCI and the entire IBD community in this important campaign to improve the lives of people with IBD in Ireland."

<u>Read the full report here</u> (https://testiscc.sharepoint.com/:b:/g/EeFZZWuVAJZBkuX7Ab_i7v4BnGFjZVdkiKphnvhJugNcQ?e=DMRqMq)

Region Nationwide

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Date Entered/Updated 26th May, 2025

Expiry Date 30th Jun, 2025

Source URL: https://www.activelink.ie/community-exchange/news/115828-research-reveals-60-of-people-living-with-inflammatory-bowel-disease-face-financial-difficulty