



CROHN'S & COLITIS UK

ACCESS TO TOILETS

**CROHN'S & COLITIS UK
POSITION STATEMENT
[November 2021]**

Crohn's & Colitis UK Position Statement: Access to Toilets

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“The availability of toilets is vital to the wellbeing and quality of life for people with Crohn’s Disease and Ulcerative Colitis.”

Our vision

We believe that everyone living with Crohn’s and Colitis should have access to publicly available toilets, free of charge and without fear of public prejudice and discrimination. Access to toilets is essential to people with Crohn’s, Colitis and other hidden disabilities accessing education, work, and social activities. This is a matter of personal and public health, equality, and social inclusion.

Key points

- Over 500,000 people in the UK are living with Crohn’s and Colitis, the two main types of Inflammatory Bowel Disease (IBD). The most common symptoms of these often-debilitating conditions are urgent and frequent diarrhoea, pain, and fatigue. As many as three in four people with Crohn’s or Colitis have experienced bowel incontinence. Access to clean, hygienic toilets is crucial to improving the quality of life of people living with these conditions.
- Nearly 9 in 10 people with Crohn’s and Colitis plan journeys based on access to toilets (87%).
- In Crohn’s & Colitis UK’s 2020 Life in Lockdown survey, over half of people (57%) with Crohn’s and Colitis were concerned about leaving their house during the pandemic, even when permitted, due to limited access to public toilets.
- 86% of respondents to a charity-wide membership survey said that access to toilets was an issue that impacted their lives.
- 70% of respondents to a survey on travel and IBD said they worried about toilet facilities whilst travelling and 63% worried about toilet facilities at their travel destination.
- 1 in 2 people with Crohn’s or Colitis report having experienced discrimination for using an accessible toilet, with over 60% of these instances including either verbal and or physical abused.
- Around 20% of people living with IBD have stoma bags. A fully enclosed cubicle with disposal facilities and a sink to change their stoma bag comfortably, hygienically and in privacy, is essential.

Why is this an issue?

“I suffer from Crohn’s disease and need access to public toilets in order to carry out my everyday life.”

Crohn’s and Colitis are lifelong diseases of the gut. They are painful, debilitating and widely misunderstood. And there is no known cure. Crohn’s and Colitis don’t just affect your gut. They can affect almost every part of your body and every aspect of your life: from your digestion and joints to your energy levels and mental health.

Over 500,000 people in the UK are living with Crohn’s and Colitis. The main symptoms of these often-debilitating conditions are urgent and frequent diarrhoea, pain, and fatigue. As many as three in four people with Crohn’s or Colitis have experienced bowel incontinence. This can mean that one second you feel okay, the next you need to go immediately. Therefore, quick access to suitable toilet facilities is crucial, either to prevent or act should an accident occur.

Additionally, 20% of people living with Crohn’s or Colitis have stoma bags and may require extra space to change and dispose of equipment comfortably, hygienically and in privacy. This requires a fully enclosed cubicle with access to a sink and disposal facilities. Sometimes people with Crohn’s or Colitis have part of their bowel removed during surgery and need a new way of getting rid of faeces (poo). The surgeon will make an opening through the person’s abdominal wall and bring the end of the bowel through the skin. This is the stoma. The poo is then collected in a soft fabric bag which fits over the stoma and is attached to the person’s abdomen (tummy). This bag needs to be changed regularly and hygienically.

Understandably, people experiencing these distressing symptoms often suffer from considerable anxiety about suddenly needing the toilet and having very little time to find one.

Experiencing an episode of incontinence in public is profoundly embarrassing. The fear of incontinence or of being unable to locate a toilet can have a significant impact on mental wellbeing and lead to social isolation through people choosing not to risk leaving their home.

“Using a toilet should not be a privilege. As someone with Ulcerative Colitis, I fully rely on public toilets in order to leave my house.”

Everyone needs a toilet. The provision of publicly available toilets is a service upon which many people with Crohn’s, Colitis and other long-term health conditions rely to enable them to engage in daily activities that others would take for granted. Not addressing the shortage of toilets disproportionately affects the most vulnerable in society. It is a matter of personal and public health, equality, and social inclusion.

What's the evidence?

Crohn's & Colitis UK are the voice of people affected by the condition - we hear time and time again how this is an issue. Surveys have consistently highlighted the crucial role that access to toilets plays in the life of people with Crohn's or Colitis and other long term health conditions.

- 86% of respondents to a charity-wide membership survey told us access to toilets was an issue that impacted their lives.
- A survey of 1,776 people living with Crohn's and Colitis found that 70% of respondents worried about toilet facilities whilst travelling and 63% worried about toilet facilities at their travel destination.
- 1 in 2 people with a hidden disability reported having had a negative reaction from the public for having used an accessible toilet, with 61% of those negative experiences having included verbal and/or physical abuse.
- 80% of people with Crohn's or Colitis feel more confident when visiting a venue with the Not Every Disability is Visible sign installed.
- Crohn's & Colitis UK's 'Life in Lockdown' survey in revealed that over half (57%) of respondents were concerned about leaving their house, even when regulations allowed, due to concerns about accessing a toilet.
- The number of public toilets across the UK is declining. In 2018 there were 4,486 operated by major councils in the UK, down from 5,159 in 2010.
- With ever-growing demands on council budgets, innovative additional solutions such as Community Toilet Schemes, are required to ensure access to appropriate numbers of publicly available toilets is maintained. Such schemes are important but should complement, not replace, public toilets which remain open during evening and weekends.

“Taking the P****” a 2019 Report by the Royal Society for Public Health concluded:

- The increasing decline in public toilets is a threat to health, mobility, and equality.
- The lack of public toilets disproportionately affects people with ill health or disability, the elderly, women, outdoor workers and the homeless.
- Knowledge of lack of facilities nearby acts as a 'loo leash', deterring as many as one in five (20%) from venturing out of their homes as often as they would like. This rises to over two in five (43%) among those with medical conditions requiring frequent toilet use.

- Over half (56%) of the public restrict fluid intake due to concern over lack of toilet facilities. Deliberate dehydration can seriously affect health and exacerbate existing medical problems.

Personal story

Femi is 26 years old and lives with Crohn's.

“Whatever I do, whether through work or socially, I always make sure it's easy for me to get to a toilet. A lot of public toilets are often unclean which isn't very nice. Usually, I'll try and find a shopping centre, but shopping centres usually close around the end of the working day, so if I'm out in the evening I really struggle as restaurants and cafes are very hit and miss.

I've been living with Crohn's for 10 years and, unfortunately, I don't have much confidence left when it comes to asking to use a restaurant or café's toilet. A lot of the time people say no. I have a Can't Wait Card from Crohn's & Colitis UK, but sometimes even that doesn't work. If people don't know about Crohn's or Colitis, then it doesn't matter what you have or what you show as people don't appreciate why you need to use a clean, private toilet urgently. That does make you wary of asking because it can be quite humiliating to be turned away when you urgently need to use the toilet. It's not a nice feeling.

There needs to be more investment in public toilets, and better awareness of invisible disabilities so everyone can understand why someone with Crohn's or Colitis needs to use the toilet urgently.'

What are we doing?

- We will continue to work across the UK to ensure that access to toilets is considered as an equality, social inclusion, and health issue.
- We will continue to work with parliamentarians in the four UK nations to call for a statutory duty on local authorities to ensure appropriate access to toilets in their areas.
- We will continue to lobby for easy digital access to information on the location and type of publicly available toilets and promote effective and innovative means of delivering this.
- We will continue to work with those in the transport and travel sectors to ensure that people with Crohn's and Colitis have the confidence to travel in unfamiliar environments, are treated with dignity and understanding, and can access a toilet when needed.
- We will continue to work with like-minded charities, organisations, and other stakeholders to raise awareness that Not Every Disability is Visible. We will promote the roll out of accessible toilet signage and related staff training in

places of employment, as well as in high footfall public areas such as public buildings, retail, transport hubs, food outlets and cultural venues.

Recommendations

- Access to toilets should be treated as a public health issue by governments across the UK.
- National and local decision-makers in all four nations of the UK should take action to increase the number of publicly available toilets. This should include increasing the number of available toilets in public spaces, on public transport and in commercial premises.
- Local authorities should have a statutory duty to ensure there is a sufficient supply of well-maintained, publicly available toilets in their area, so people with disabilities, whether hidden or visible, do not face and social exclusion and isolation.
- Local authorities should take the lead role in facilitating and publishing information detailing access to local toilets. This information should be available digitally and include details of what facilities are available at each location.
- People with Crohn's or Colitis should be able to access toilets in shops, restaurants, and other buildings, without having to explain themselves. The Crohn's & Colitis UK Can't Wait Card is a way to support this, but we need to work towards a society where all you need to do is ask.
- Not Every Disability is Visible accessible toilet signs should be a requirement in all venues. This will help change public perceptions of disability, end stigma and ensure everyone who needs to use an accessible toilet can. Education is needed, alongside the signage, with staff trained to support their customers in a helpful, discreet, and understanding way. (Signage and training materials are available from Crohn's & Colitis UK).
- Anyone with an invisible disability, including people with Crohn's or Colitis, should have the confidence to use accessible toilets free from challenge or discrimination. It is essential that people living with Crohn's and Colitis feel confident to leave their homes to go about their daily life including travelling to unfamiliar environments, safe in the knowledge that they will be able to access a toilet when needed.
- A Blue Badge can enable someone with Crohn's or Colitis to park a short distance away from their work and other facilities in case they need to access a toilet quickly. Despite changes to the Blue Badge criteria which aim to take invisible disabilities more into account, unless they have medical evidence to demonstrate psychological distress most councils will not consider people with Crohn's or Colitis eligible for a Blue Badge. We would like to see continence

issues taken into consideration in the same way as mobility and mental health in the eligibility criteria for Blue Badges and through local authority toilet strategies as part of delivering on public health across the UK.

About us

We are the leading UK charity for people with Crohn's and colitis. We are working to improve diagnosis and treatment; to fund research into a cure; to raise awareness and to give people hope, comfort and confidence to live freer, fuller lives.

Contact us

To comment or respond to our position statement please contact:
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