

***HEALTH SCRUTINY  
Overview & Scrutiny Committee  
Supplement***

Date Tuesday 8 December 2020

Time 6.00 pm

Item No

12 Council Motion: Not every disability is visible (Pages 1 - 4)  
Crohn's and Colitis UK briefing paper

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## Crohn's & Colitis UK's Not Every Disability is Visible campaign

### About us and invisible conditions

- [Crohn's & Colitis UK](#) is the UK's leading charity for Crohn's and Colitis. We're here for everyone affected by Crohn's and Colitis.
- Right now, an estimated 500,000 people in the UK are living with a lifelong disease that many people have never heard of.<sup>1</sup>
- Moreover, there are over 11 million disabled people in the UK<sup>2</sup>, and an estimated 1 in 7 people are living with an invisible condition<sup>3</sup>. Whether you realise it or not, some you know lives has a hidden condition.
- Because of the stigma and misunderstanding surrounding invisible conditions, people are suffering in silence and being discriminated against for trying to use accessible toilets.

### About the conditions

- This [short video](#) explains the conditions.
- Crohn's Disease and Ulcerative Colitis – the two main forms of Inflammatory Bowel Disease – are lifelong diseases of the gut. They are painful, debilitating and widely misunderstood. And there is no known cure.
- When you have Crohn's or Colitis, your immune system doesn't work properly. Your body starts attacking itself, causing ulcers and inflammation in the gut.
- One of the main symptoms, but by no means the only one, is the frequent and urgent need to use the toilet to poo.
- These lifelong diseases don't just affect the gut. They can affect many parts of the body – from eyes, joints and the liver to mental health. And they can affect many parts of life – from education and work to relationships.
- People living with the conditions face a lifetime of medication and, in many cases, major surgery.
- Surgery could include constructing a stoma. A stoma is where the diseased part of the gut is removed and the remaining healthy part of the gut is brought out through a small opening in the abdomen. Digestive waste (poo and liquid) can then be collected in a bag outside of the body.

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<sup>1</sup> IBD UK - Information for Patients. Accessed at: <https://ibduk.org/information-for-patients>. Last accessed November 2020

<sup>2</sup> <https://www.gov.uk/government/publications/disability-facts-and-figures/disability-facts-and-figures>

<sup>3</sup> <https://www.psychreg.org/invisible-disabilities/>

## Not Every Disability is Visible campaign - what is the problem?

- People with Crohn's or Colitis and other invisible conditions can outwardly 'look-well', and do not meet some people's outdated perception that disabilities must be visible.
- Because of this incorrect perception 1 in 2 people with Crohn's or Colitis have had a negative experience from members of the public just for using an accessible toilet<sup>4</sup>. And of these negative experiences 61% included verbal and or physical abuse<sup>5</sup>.
- Interestingly our survey shows that over 80% of people who challenge healthy-looking people using accessible toilets think they are 'standing up' for the rights of disabled people or that it's 'not fair' on others<sup>6</sup>.
- We believe that education is the key - through changing [accessible toilet signage](#) and training staff we're challenging the stigma.

## Campaign History and benefits

- This video gives a [short history of the campaign](#).
- The campaign has won numerous awards including in 2020 two Communique awards for Public Health Communications and Excellence in Media Relations.
- The *Not Every Disability is Visible* campaign was originally inspired by Grace Warnock, who lives with Crohn's Disease. At the age of 11, Grace found herself facing judgment from strangers when using accessible toilets in public. Determined to change this, Grace created her own accessible toilet sign that was more inclusive of people with invisible disabilities.
- Our campaign has gone from strength to strength, with over 3,000 venues across the UK installing our signage. Supermarkets, restaurants, entertainment venues and travel hubs alike have joined the campaign. Supporters include Asda, Morrison's, Tesco, Waitrose and Sainsbury's as well as Nando's, Wetherspoons, Gatwick Airport and Moto Hospitality to name but a few.
- Pledging to the campaign is a small gesture with a huge positive impact on the community: **83% of people with Crohn's and Colitis said that they felt more comfortable visiting places with the Not Every Disability is Visible signs.**<sup>7</sup>

## Sign costings

- We have large temporary stickers of the sign that we can provide you.

<sup>4</sup> Immunology\_DoF\_25Jan2019\_MI\_PC\_001 (unpublished data from Toilet Consortium UK's 2017 Survey, July 2017)

<sup>5</sup> Immunology\_DoF\_19MAR2019\_MI\_SG\_001 (unpublished data from Not Every Disability is Visible 2019 Patient Survey, March 2019).

<sup>6</sup> Immunology\_DoF\_08MAR2019\_PC\_002 (Not Every Disability is Visible 2019 Public Survey, March 2019).

<sup>7</sup> Crohn's & Colitis UK campaigner survey, November 2019

- For more permanent signage, quotes from trusted Oldham business [Simply Signs](#) suggest prices could be as cheap as £12.50 each to create and install.
- Companies have either used our signs or incorporated the sign into their own brand. You can see some examples [here](#).

## Supporting you

- We have a volunteer group in the South Manchester area, they could form part of a working to help implement the signs and staff training.
- We'd be happy to provide training to educate staff on the conditions.
- We'd be happy to advise and review your final signs.
- Upon installation of the signs and commitment to train staff we'd publicise across our channels your involvement in the campaign.

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