

Inflammatory Bowel Disease

3 steps towards greater equality



MANIFESTO FOR WALES

2021

Inflammatory Bowel Disease:

Three steps towards greater equality

Crohn's Disease and Ulcerative Colitis, the main forms of Inflammatory Bowel Disease (IBD), are lifelong diseases of the gut which affect an estimated 25,000 or 1 in 117 people living in Wales.

They are painful, debilitating 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 the ability to work.

There is no known cure.

However, as well as having an invisible, life-long health condition that is unpredictable and fluctuates in severity, people with Crohn's and Colitis face other variations which are beyond their control and make living with their condition even harder.

fluctuate (verb)

fluc·tu·ate

Definition of fluctuate

intransitive verb

1. to change, especially continuously and between one level or thing and another
2. to shift back and forth uncertainly.
3. to rise and fall in or as if in waves.

We are calling on the Welsh Government to actively promote equality for people with Crohn's and Colitis by working with others to reduce unnecessary variation in provision across Wales

Visit www.crohnsandcolitis.org.uk to find out more about these debilitating lifelong conditions

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variation (noun)

var·i·a·tion

Definition of variation

noun

1. a change in amount or level
2. something that is slightly different from the usual form or arrangement:
3. change in quality, amount, or level

Health services

Health services for people with IBD vary in quality and content across Wales and when compared across the four nations of the UK.

Toilets

Access to public and accessible toilet provision is essential to work, leisure, education and travel when urgent and frequent diarrhoea is a clinically recognised symptom of your condition. But such provision varies widely across Wales, both in the built environment and on public transport.

Employers

Employers, schools and other education institutions vary in the level of reasonable adjustments they make for employees, pupils and students who have fluctuating long-term conditions such as Crohn's and Colitis.

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I recently went for a walk in the park as it felt safe as it was an open space. I noticed all the toilets including the disabled toilets were shut off, which upset me as halfway through our walk, I had the normal urgency to go to the loo so we had to leave and go home. I feel very prohibited. Where I can go now? It's very disheartening.

Toni Kelly, 43, living with Crohn's

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Whilst recent months have undoubtedly been hard, COVID-19 has shown us that change is possible and can be achieved quickly when the political will exists.

Health

Three steps towards greater equality

Promote **equality of care** by reducing unacceptable variation in health service provision for people living with Crohn's and Colitis throughout Wales.



Prioritise rapid access to diagnosis and treatment for people with Crohn's and Colitis.



Agree a national minimum specification for staffing levels and composition of IBD multidisciplinary teams.



Develop a supported self-management programme to enable people in Wales with Crohn's and Colitis to take greater control of their condition.

inequality
(noun)

in·equal·i·ty

Definition of inequality

1. the unfair situation in society when some people have more opportunities, money, etc. than others
2. when money/opportunities are not shared equally between different groups in society
3. a lack of equality or fair treatment in sharing wealth or opportunities

Toilets

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Promote **equality of access** by ensuring that people with Crohn's and Colitis can access free, clean, publicly available toilets across Wales when they need them.



1) Ensure that provision of public toilet facilities across Wales is prioritised and enhanced through the active strategic integration of Y Llwybr Newydd – The New Transport Strategy and existing Local Toilets Strategies.

2) Ensure that Local Authorities are required to provide easily accessible, 'live' information on the availability of public toilets in their area

3) Commit to requiring all accessible toilets, whether in private or public buildings, to display Not Every Disability is Visible signage

Harness innovation and new ways of working post COVID-19

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Promote **equality of opportunity** by ensuring that the new choices which emerged for people with Crohn's and Colitis during the COVID-19 pandemic around flexible working, study and access to healthcare are built into service recovery and 'resetting' agendas across all policy sectors in Wales.



1) Working with the education sector, ensure that remote learning material and resources are readily available for students with fluctuating long-term health conditions, when they are unable to attend school or college at short notice

2) Working with employers, ensure that reasonable adjustments are available for people with fluctuating long-term health conditions so that they are able to retain the choice of flexible working when required



3) Promote the increased use of remote health monitoring and access options to both improve the patient experience and reduce demand on secondary care services

What can YOU do?

Steps YOU can take towards greater equality



Speak to us

1. Speak to us. We can provide you with insights into the lived experience of people with Crohn's and Colitis and the impact these long-term health conditions have on employment, access to health care, education, travel, etc.

Speak up

2. Speak up for equality on behalf of people with Crohn's and Colitis. Use the resources on our website to raise the issue of IBD with your Health Board and in The Senedd. Check out how your local IBD service is meeting the 2019 IBD Standards.



[ibduk.org/
services-map](http://ibduk.org/services-map)

Speak out

3. Speak out to challenge outdated perceptions of disability – join our Not Every Disability is Visible campaign and help ensure that all public services, businesses and employers display our Not Every Disability is Visible signage. Help make the invisible, visible.

Around 25,000 people in Wales have IBD – you will be helping someone you know.

Our vision and mission

We're Crohn's & Colitis UK.

THIS IS OUR VISION (WHERE WE WANT TO GET TO):

Improved lives today,
and a world free from Crohn's
and Colitis tomorrow.

THIS IS OUR MISSION (HOW WE'RE GETTING THERE):

We break taboos. We drive pioneering
research. We bring people together. We
campaign to improve lives. We lead the
fight against Crohn's and Colitis.

1 Crohn's Disease and Ulcerative Colitis are lifelong diseases of the gut

They are the two main forms
of Inflammatory Bowel
Disease and both of them are
painful, debilitating and
widely misunderstood.

2 When your gut doesn't work, the consequences can be devastating

These can impact every
aspect of your daily life,
from digestion and joints
to energy levels and
mental health.

3 Symptoms can affect almost every part of the body

They can include;
frequent/urgent diarrhoea, often
with blood and mucus; severe
pain; extreme fatigue; dramatic
weight loss, swollen joints, mouth
ulcers and more.

4 Crohn's and Colitis affect many people all over the UK

New research suggests at
least 500,000 people live with
these conditions across the
UK, which is an increase from
previous findings.

5 Many people are diagnosed before the age of thirty

This means young people can
experience effects on their
development as well as their
relationships, education and
work prospects.

6 There is no known cure for Crohn's or Colitis

Once diagnosed, people often
face a lifetime of fluctuating
symptoms and remission,
medication and, in many
cases, major surgery.

For further information, please contact Wayne Lewis, Policy Lead (Wales):
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