

# IBD Science Communication Plain Text

Inflammatory Bowel Disease (IBD):Ulcerative Colitis and Crohn's Disease, Brought to you by The LUNA Project, as part of our *Science Communication Project*

## Definition

Inflammatory Bowel Disease (IBD) includes Ulcerative Colitis (UC) and Crohn's Disease. These are conditions that affect the digestive system. The digestive system (also called guts or bowels) is a long tube in your body that allows you to eat food and remove waste from your body.

In UC and Crohn's parts of the digestive system become inflamed, creating ulcers that can bleed. This can cause tummy pain, vomiting, nausea (feeling sick), blood or mucus in stool (poo), diarrhoea (needing to go to the toilet to pass stool lots), constipation (finding it hard to pass stool), and fatigue (feeling tired all the time).

UC affects the last parts of the digestive system called the large intestine (also known as the colon) and the rectum. Crohn's disease can affect any part of the digestive system from the mouth to the anus, often people with Crohn's have multiple different parts of their digestive system affected at one time, e.g. their mouth and stomach.

UC and Crohn's are chronic and relapsing conditions. This means that people with UC and Crohn's have periods where they feel well and periods where their UC 'flares up' and they become unwell. There is currently no cure for UC or Crohn's; although some people can go years without experiencing a flare if they take medication.

## References

<https://www.stmarkshospitalfoundation.org.uk/how-we-are-saving-lives/statistics/#:~:text=Inflammatory%20Bowel%20Disease&text=Around%20the%20world%205%20million,210%20people%20in%20the%20UK.>

<https://www.crohnscolitisfoundation.org/sites/default/files/2019-02/Updated%20IBD%20Factbook.pdf>

## Causes

The cause of IBD is unknown but it is thought that people's genes can increase their chance of having IBD. This means people who have family members or close relatives with Crohn's or UC are more likely to have Crohn's or UC themselves.

Other factors include different factors in the environment, how the immune system responds to infections and the bacteria which are found in the gut.

## Who is affected?

Around 300,000 people in the UK have IBD, that's about 1 in every 210 people!

Although IBD can affect anyone of any age, most people have their first flare-up and are diagnosed between the ages of 15-30 years old.

IBD affects males and females roughly equally.

## References

<https://www.stmarkshospitalfoundation.org.uk/how-we-are-saving-lives/statistics/#:~:text=Inflammatory%20Bowel%20Disease&text=Around%20the%20world%205%20million,210%20people%20in%20the%20UK.>

<https://www.crohnscolitisfoundation.org/sites/default/files/2019-02/Updated%20IBD%20Factbook.pdf>

## Signs and Symptoms

There are many symptoms people may experience due to IBD. Commonly, individuals will experience diarrhoea (increased frequency and/or loose stools), pain in the tummy, losing weight, feeling tired and/or noticing blood in their stool. All of these symptoms can be worrying and may have a big impact on everyday life. These symptoms may also lead to feeling embarrassed, however, it is important to understand that healthcare professionals will be considerate and understanding when talking about potentially uncomfortable things.

As well as the symptoms mentioned above, IBD can cause many other signs or symptoms affecting all areas of the body. The table below summarises some of the many symptoms that someone may experience and what area of the body is involved. The symptoms of Crohn's Disease and Ulcerative Colitis are very similar, however, some are more common to each disease.

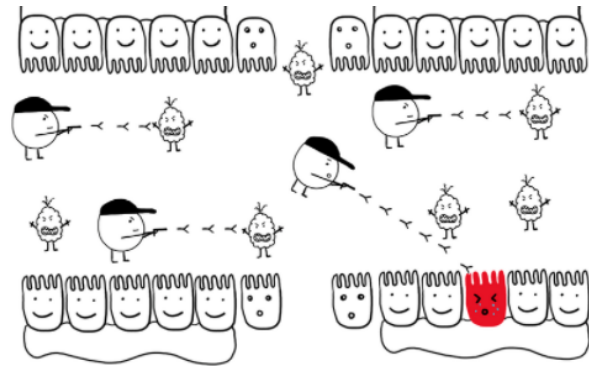
<b>Area of the body</b>	<b>Signs &amp; Symptoms</b>
General	Weight loss or not growing as expected* Fever Feeling generally unwell Tiredness/fatigue Nausea & vomiting Loss of appetite
Bowel Habits (going to the toilet)	Diarrhoea Frequency (going to the toilet more often) Blood in stools** Mucus in stools*

	<p>Urgency</p> <p>Nocturnal defecation (going to the toilet at night)</p> <p>Tenesmus (persistent, painful urge to go to the toilet, even when the rectum is empty)</p>
<p>Abdominal (tummy)</p>	<p>Abdominal pain (cramping and tender)</p> <p>Bloating</p> <p>Abdominal mass</p> <p>Perianal disease e.g. abscesses, fistulae, skin tags) that causes pain and/or blood when wiping.</p>
<p>Extra-intestinal (other areas of the body)</p>	<p>Joints- arthritis; causes painful, red, swollen joints.</p> <p>Eyes- inflammation of the eye (uveitis** or episcleritis*)</p> <p>Skin- tender, red/violet areas of the shin (erythema nodosum)</p> <p>Mouth ulcers*</p>
<p>*More common in Crohn's Disease</p> <p>**More common in Ulcerative Colitis</p>	

### Pathophysiology - Ulcerative Colitis

Ulcerative colitis is a condition where ulcers (a sore which is an open painful wound) form on the lining of the bowels (where the nutrients from our food are absorbed). It is an autoimmune disease which means it's caused by the body's own immune system.

Our first defence against pathogens (they make us ill) is something called our mucosal layer. With Ulcerative Colitis some of this layer in the bowels has holes in it, this means that the pathogens can get into our bowels. But our bodies are clever! They have little helpers called B cells that attack the pathogens with little chemicals called antibodies. But sometimes the helpers get carried away in all the action and they accidentally end up hitting our own cells, this is what causes the painful ulcers. This results in lots of inflammation and other cells in the immune system being activated which then all get involved and continue to keep the inflammation going. If this inflammation keeps going you can get changes in the structure of the bowel which can add to symptoms.



## Investigations

When Doctors think somebody might have inflammatory bowel disease, the next step is for them to do some tests/investigations. These tests help check for things such as anaemia (low levels of red blood cells), inflammation of the bowel and specific changes to the bowel that occur in IBD. Some tests may also be done to rule out other causes of an individual's symptoms such as blood tests to check for Thyroid Disease, Coeliac Disease and other autoimmune (when an individual's immune system attacks part of their own body) diseases. The table below describes some of the common tests that a Doctor may wish to do. Some of these investigations can cause some distress and may cause you to feel worried; make sure to speak to your Doctor if you have any questions or concerns.

Type of Investigation	Investigation	Explanation
Blood Tests	Full Blood Count,	Check for anaemia (low levels of red

	<p>iron studies, vitamin B12 &amp; folate</p> <p>Urea &amp; Electrolytes and Liver Function Tests</p> <p>ESR/CRP</p>	<p>blood cells) and levels of iron, ferritin, folate and B12 in the blood.</p> <p>Check for dehydration, electrolyte levels, liver enzymes, proteins in blood and more.</p> <p>Inflammatory markers that check for levels of inflammation in the body; raised in infection or inflammatory disease.</p>
<p>Stool Sample</p>	<p>Microscopy, culture &amp; sensitivity, Clostridium difficile (type of bacteria) and faecal calprotectin</p>	<p>Checks for infection of the bowel and inflammation of the bowel. Faecal calprotectin is released by the bowel/intestines when it is inflamed and is increased in 90% of cases of IBD.</p>
<p>Endoscopy or Colonoscopy</p>		<p>An endoscope (long thin tube with camera on the end) is inserted down the throat (OGD) or up the back passage (colonoscopy) which allows doctors to look at the inside of your intestine. They are the best way to diagnose IBD. Doctors will also take a small piece of your bowel wall and send this off to the lab for them to look at under a</p>

		microscope and this allows them to see if you have CD or UC.
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## References

<https://www.crohnsandcolitis.org.uk/>

## Treatments

Treatments are getting better all the time! There are 2 main forms of treatment - those to help symptoms and those which stop the underlying process.

- Some people are given medication that helps calm down the B cells and other cells in the immune system, reducing the damage to our own cells.
- Some people are also given tablets to help calm down inflammation quickly, these are called steroids.
- Some people manage their diets and avoid eating certain things such as raw fruit and vegetables and dairy amongst other things.
- Some people are treated through liquid diets and feeding tubes which can make sure bodies are getting the fuel it needs and gives the organs involved time to rest.
- You might need to take supplements to replace the nutrition that your body can't absorb.
- Pain killers can also be used.
- Some people need to have an operation called a Colectomy which takes out the part of their bowel that has been damaged.

## What effects does treatment have on daily life?

- Some people need to take a lot of tablets during the day.

- Some medication has side effects. As everyone reacts differently to medication you should always let your team know if you are having particularly problematic side effects.
- If someone has had a Colectomy they might have a little bag that is attached to their stomach, this is where faeces (poop) are collected as it is dangerous if faeces are left in the body with no way out!

## References

<https://kidshealth.org/en/parents/ulcerative-colitis.html#:~:text=Ulcerative%20colitis%20is%20a%20condition,or%20constantly%20comes%20and%20goes.>

## Psychological Effects

People with IBD have been shown to have a higher rate of depression and anxiety than the general population or people with other illnesses. This can be a result of a combination of physiological effects and socioeconomic factors.

### The Brain-gut Axis

Research has shown a relationship between the brain and the gut. Inflammation in the gut can lead to changes in brain functions such as loss of appetite, changes in circadian rhythm, resulting in loss or change in sleep and mood disorders, such as anxiety and depression.

### Depression

Flare-ups and inflammation can contribute to depression in people with IBD and the mental exhaustion of illness and pain every day, along with hospital visits can add to feelings of depression. Other factors such as being unable to attend work, can create a



financial burden and also can have an impact on self-worth. Not being able to attend school and university or socialise as often as one used to can also lead to depressive symptoms, such as low self-esteem, lack of interest in things you used to love, feelings of anger, hopelessness and emptiness.

## Anxiety

Feelings of panic and worry can become overwhelming with IBD. The physical demands of IBD symptoms, flares and pain and low energy can cause mental and emotional stress regarding keeping up with work or school responsibilities and deadlines. Being caught out by a flare-up when you are away from home can be very stressful and can cause a lot of negative thoughts, worries and frustration.

Anxiety around the availability of bathrooms, taking enough supplies and medication when out and about can produce a regular state of anxiety with IBD. Even if you are prepared it can still be an anxious experience to be out and about and always requires forethought. If you feel anxious when you are away from home but you are prepared and in a safe environment this may be a sign of anxiety.

You might have thoughts like: “Something bad will happen.” “I’m going to be embarrassed.” “But what if something goes wrong?” “I’m getting sick.”

## References

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[https://journals.lww.com/ajg/fulltext/2011/09000/Increased\\_Risks\\_of\\_Developing\\_Anxiety\\_and.18.aspx](https://journals.lww.com/ajg/fulltext/2011/09000/Increased_Risks_of_Developing_Anxiety_and.18.aspx)

<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4512611/>

<https://www.crohnscolitisfoundation.org/mental-health/depression-anxiety>

<https://www.nhs.uk/conditions/clinical-depression/symptoms/>

## Societal Challenges

### Internalising others perceptions

Many perceive IBD as a 'taboo' subject and consequently anticipate negative reactions from others. Research showed that people with IBD feel they are different from others and that others would perceive them negatively and that their peers may treat them differently.

Perceived stigma has been shown to produce poorer outcomes in patients with IBD when controlling for illness and demographic variables. Perceived stigma is a potentially important psychosocial factor in IBD patient care and warrants further investigation.

### Psychological adjustment

For people living with IBD, a poorer psychological adjustment was reported by those who held more negative perceptions and reactions toward their illness.

In a meta-analysis of the CSM, Hagger and Orbell (2003) reported that a strong illness identity (e.g. viewing one's disease as having severe consequences and as symptomatic) was associated with negative outcomes such as using maladaptive coping strategies and poorer psychosocial wellbeing

.In contrast, perceiving the illness as controllable was associated with problem-focused coping and improved psychological wellbeing. These findings demonstrate the significant impact that negative illness perceptions can have upon an individual's coping and psychological health.

Having to be prepared all the time and constantly having to think about whether there will be access to a toilet or whether you have all the supplies and medication you need when you are out can be very stressful and exhausting.

## Effects on school, work and relationships

The symptoms of Crohn's and colitis can have a major impact not only on your physical health but on your emotional and mental wellbeing. Fatigue and sickness can be very tiring and can have a major impact on your day-to-day life. This can affect things like attendance at school, university or work. This can become a source of stress for people and can leave you feeling behind at work.

The symptoms and side effects of IBD can change a social life drastically. With less energy and the complications of bowel movements and eating requirements, certain activities that you participated in before with your friends might not be possible now or require a substantial amount of energy to participate. 65.1% said that UC caused them to miss out/influenced leisure activities, and 9.9% said that it had influenced relationships with relatives/friends.

## References

<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2938734/>

<https://academic.oup.com/ibdjournal/article/19/7/1450/4604313?login=true>

<https://www.tandfonline.com/doi/abs/10.1080/088704403100081321>

<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6154710/>

## Effects After Remission

Research shows that the quality of life for people with IBD increases after treatment or remission. These studies measure the quality of life by the severity of illness, functional impairment, employment status and severity of symptoms. Improved quality of life after

treatment means you can maintain a steady job, are re-energized for socialising and maintaining healthy relationships and generally you aren't as sick as you once were. For most people quality of life increases after recovery via an ostomy or other treatment, however, there are still many difficult adjustments to be made. People with Crohn's and other bowel diseases experience severe illness before they are treated. Therefore most people see an ostomy or other treatments as a welcome change and a saviour from a very difficult illness but that doesn't mean that life after treatment is an easy adjustment.

There is a common misconception in the medical world that once you've received treatment and are in remission that your life is automatically better. Medical treatments are very important for IBD as they can improve your ability for your body to function. I.e. participate in school, socialise, maintain a job, which are all very important in feeling fulfilled but what can go unnoticed are the psychological effects of the change in your life.

Although you may feel like you are back on track with school or work and may be at the same level in these respects as your peers, your life is different to theirs and is different to your life before IBD.

## Grieving

Feelings of anxiety and sadness after your remission may be due to an unacknowledged loss in your life. This is common in people with disabilities and is a very similar process to the process of grief. Grieving the life you used to have and the things you may no longer be able to do. There are 5 stages of grief and it isn't a linear process and can occur throughout the life of a disabled person. Often triggered by things you thought you would be able to do but can't. The stages can jump around and go back and forth depending on triggers and different events in your life.

In the Denial stage, you may be trying to keep up to a standard that you previously had managed or to the level you perceive you should be at now that you are in remission and "well" again. This can then lead to the Anger stage and resentment when that level

is no longer sustainable and you realise things aren't quite the same as before. The Bargaining stage can manifest itself in feelings of guilt and shame about feeling overwhelmed and sad about your life now you are in remission. The depression stage can lead to feelings of hopelessness and can result in feelings of pointlessness because of one thing you can no longer do. During this stage, you're often overcome with the emotions that you were trying to avoid in the previous stages of grief, and it can feel foggy and confusing. The acceptance stage isn't always a final destination. As you move through life you may move back a stage or start the process over again when these feelings arise somewhere new.

## References

<https://connect.springerpub.com/content/sgrjarc/48/2/15>

<https://www.sciencedirect.com/science/article/pii/S1067251614003032>

## History

In 1932, gastroenterologist Burrill B. Crohn and his colleagues Leon Ginzburg and Gordon D. Oppenheimer identified the condition now known as Crohn's disease, which Crohn called ileitis (meaning inflammation of the ileum).

Prior to the report, the condition was thought to be a type of tuberculosis and not an inflammatory bowel disease.

In addition to helping define the disease that bears his name, Crohn was one of the first medical professionals to link gastrointestinal distress to anxiety.

He also published a book with the charming title *Affections of the Stomach* in 1927 and commented in media reports when President Dwight D. Eisenhower came down with ileitis symptoms in 1956.

## References

<https://www.crohnscolitisfoundation.org/>

<https://www.news-medical.net/health/History-of-Crohn's-Disease.aspx>

## Development and Risk Factors

Children are twice as likely to be diagnosed with Crohn's as UC.

Active smokers are more than twice as likely as nonsmokers to develop Crohn's.

Some studies have shown that the disease is becoming more prevalent, especially in Western countries and in children. Researchers think the "Westernized lifestyle" of poor-quality diet and lack of exercise are contributing factors to the increase.

## How Crohn's affects people differently

About 10% to 20% of people with Crohn's disease have at least one other family member who also has the disease.

Crohn's is also more common among certain ethnic groups, such as Jewish people, and is more prevalent in Caucasians.

Adults with IBD are more likely to live with other chronic conditions than those without IBD.

## References

<https://www.webmd.com/ibd-crohns-disease/crohns-disease/qa/who-is-most-likely-to-have-crohns-disease>

<https://www.mentalfloss.com/article/582241/crohns-disease-facts>

## About the Authors

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## Get Involved

We would love to get as many people involved in creating these resources, or involved in any other aspect of LUNA, as possible! You can email us at [thelunaproject@gmail.com](mailto:thelunaproject@gmail.com) or find us on social media [@thelunaprojectuk](https://www.instagram.com/thelunaprojectuk) to find out more!

