LET'S TALK endoscopy

A Shared Language For Inflammatory Bowel Disease (IBD) Care

Let's Talk Endoscopy is an educational resource developed and funded by Johnson & Johnson in partnership with the International Federation of Crohn's & Ulcerative Colitis Associations (IFCCA).

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A Shared Language for Inflammatory Bowel Disease (IBD) Care

Endoscopy is one of the most important tools for diagnosing, managing, and treating inflammatory bowel disease (IBD), including **Crohn's disease (CD)** and **ulcerative colitis (UC)**.[1] It allows doctors to see inside your **gut** so they can understand how the disease is behaving (endoscopic **disease activity**)[2,3] and decide on the best treatment for you.[4] This is important because **inflammation** can be present even when symptoms are mild or not noticeable.[5]

There are some common myths about using endoscopy to manage IBD over the long-term, and some medical terms used can cause confusion.[6] This guide explains the key terms* that you may come across throughout your experience, from diagnosis to long-term remission.

You can learn more about terms ***highlighted*** *by clicking on them, which will take you to the glossary at the end of this guide.*

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This guide is an educational resource only. Talk to your healthcare team for medical advice.
*The terms included are informed by an International Federation of Crohn's & Ulcerative Colitis Associations (IFFCA) IBD patient survey and doctor/patient interviews.

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01

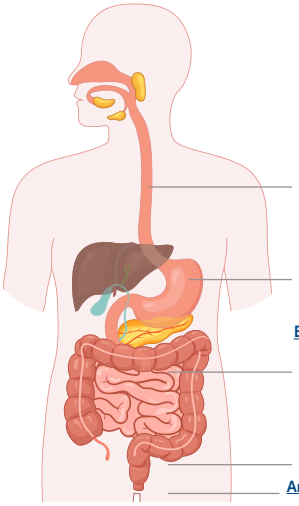
What is endoscopy?

Endoscopy is the general term for medical procedures that use a thin, flexible tube with a camera and light (called an endoscope) to look inside the **gut**.[2] In IBD, endoscopes are inserted into the mouth or **anus**,[1,2,7,8] and the doctor will slowly guide it through the intestines or stomach to view the area they need to examine.[7,8] The procedure itself usually takes 15-45 minutes, but the total visit time may vary depending on preparation, **sedation** and recovery time.[9]

What are the different types used in IBD?

The main types of endoscopies in IBD include:

Gastroscopy	Colonoscopy	Sigmoidoscopy
Examines the oesophagus, stomach, and first part of the small intestine (duodenum).[8]	Investigates the inside of the large intestine (colon), the last part of the small intestine (terminal ileum) and rectum.[7, 10]	Examines the rectum and lower part of the colon called the sigmoid colon.[11,12,13]



Oesophagus – transports food and liquids from the mouth to the stomach.[14, 15]

Stomach – stores and sends pre-digested food into the small intestine.[16]

Bowel – where nutrients are absorbed, and waste (stool) is made.[13,16]

- **Small intestine** – breaks down food and absorbs nutrients and water into the bloodstream.[16]
- **Large intestine** – absorbs water and electrolytes from indigestible food matter forming stool.[16,17]

Rectum – a storage chamber for stool.[18]

Anus – the opening where stool leaves the body.[19]

Why is endoscopy used?

Endoscopy plays a key role in the diagnosis, ongoing management, and treatment of IBD.[1] It allows doctors to look for signs of disease inside the **bowel**[10] and can be used to take a small sample of tissue (a **biopsy**).[1] The biopsy can be sent to a lab to help confirm the type of IBD that you have and how well you are responding to treatment.[1,20] Biopsies are typically pain-free and may be taken even when the bowel looks normal, because signs of **inflammation** can sometimes only be seen under a microscope.[21,22,23]

What are doctors hoping to achieve with endoscopy?

The purpose of endoscopy is different depending on the stage of disease:

At diagnosis: Endoscopy will be used to check if you have IBD, its location and extent, and if you do, which type it is (**CD** or **UC**).[1,20]

Ongoing disease management: Endoscopy helps track IBD endoscopic **disease activity** and guides decisions about your treatment.[4,5] Treatment goals are individualised and may evolve over time.[5]

Long-term remission: Endoscopy is used to monitor the health of your bowel over time.[24] Your doctor is aiming to help you reach long-term **remission** (healing) and prevent symptom **flare-ups** or further damage.[25,26]

02

Key overarching IBD terms

You can familiarise yourself with general IBD terms before reading about each stage of the disease. The definitions below explain key words you will often see throughout your care.

Types of IBD

Medical term	Definition	Alternative terms
Crohn's disease (CD)	CD is associated with chronic **inflammation** of the digestive tract, mainly affecting the **bowel** wall.[20] Inflammation appears in patches and can affect all layers of the intestinal wall.[18] Doctors use treatments to reduce inflammation, achieve **remission**, and lower the risk of complications.[25]	• Crohn's • CD • Crohn's colitis • Transmural inflammatory disease
Ulcerative colitis (UC)	UC is characterised by chronic **inflammation** of the inner lining (**mucosa**) of the colon and the development of **ulcers**.[20,27] UC almost always affects the **rectum** and inflammation (**colitis**) can spread further up the colon.[27] Doctors use treatments to reduce inflammation, achieve **remission**, and lower the risk of complications.[25]	• UC • Ulcerative inflammation of the colon • Large bowel inflammation

Clinical concepts

Medical term	Definition	Alternative terms
Disease activity	Disease activity reflects how active and damaging IBD is at a given point in time and is measured using the severity of symptoms, **inflammatory markers**, and **endoscopy**.[28,29,30] Disease activity identified during endoscopy is known as endoscopic disease activity.[28]	• Disease severity • State of disease
Flare-up	A flare-up is where IBD becomes active after a phase of inactivity (**remission**).[13] **Inflammation** in the **gut** increases, and patients experience symptoms and have an increased chance of complications.[5,13,26]	• Flare • Relapse • Active disease • Exacerbation
Remission	Remission is when the disease is inactive, meaning symptoms are absent or significantly reduced.[13] There are different types, including **symptomatic remission**, **biomarker remission**, **endoscopic remission**, **histological remission**, and **transmural remission**.[5,22]	• Symptom-free period • Stable phase • Inactive phase

03 Endoscopy at different stages of disease

This section follows the typical patient experience and introduces language to be aware of and practical advice at every stage, from diagnosis through to ongoing management and long-term remission.

3.1 Diagnosis

Undergoing **endoscopy** for the first time can feel overwhelming, but understanding the process and terms you'll encounter can help you feel more confident and prepared.[6]

What to expect

At diagnosis, your doctor will use a combination of tests and procedures to determine whether you have IBD, and if so, which type.[20] Endoscopy is a key tool, allowing them to look directly inside your **gut** and take **biopsies** to support diagnosis.[1,2]

What your doctor is looking for

Your doctor will look for the signs of **inflammation** and damage (**lesions**) associated with IBD.[1,28] The type of these lesions help them decide whether you have **CD** or **UC**.[1,28,31]

Key terms

Endoscopy preparation

Medical term	Definition	Alternative terms
Bowel preparation	Bowel preparation is the process of cleansing the **colon** of stool before **endoscopy**.[7,9] Typically, patients drink a laxative and follow dietary restrictions to empty the colon to ensure clear visibility of the inner lining (**mucosa**).[7,32] Bowel preparation can be unpleasant, but it's important to make sure doctors can accurately diagnose and monitor IBD.[6,7,9]	• Bowel prep • Bowel cleansing • Endoscopy prep
Sedation	Sedation can help patients to feel calm and comfortable during an **endoscopy**.[33] There are different types of sedation, and the experience can vary: • Conscious sedation is commonly used and helps patients feel relaxed and reduces discomfort while they remain awake.[33,34] • Deep sedation means the patient is fully asleep during the procedure and will not be aware of what is happening.[33,34] After sedation, patients may feel sleepy or experience memory loss.[9] Because of this, it's best to discuss results when the effects of sedation have resolved.[6]	• Endoscopic premedication • Monitored anaesthesia care • Procedural sedation • Anaesthesia

Endoscopy findings		
Medical term	**Definition**	**Alternative terms**
Lesions	Lesions are areas of abnormal or damaged tissue caused by injury, infection, **inflammation**, or disease.[13] Common lesions in IBD include **erosions**, **ulcers**, **polyps**, **strictures**, and **fistula**.[13,20,35] During **endoscopy**, lesions are visible evidence of endoscopic **disease activity** and help distinguish between **CD** and **UC**.[28]	• Defect • Abnormality • Damaged area
Inflammation	Inflammation in the context of IBD is when the body's immune system abnormally attacks the **gut**, causing swelling (oedema), reddening of the inner lining (erythema), and the loss of a normal vascular pattern.[3,10,13,36] This damage can be seen during **endoscopy** and may be present with or without the patient experiencing symptoms.[3,10,28]	• Immune-mediated injury • Inflammatory activity • Inflammatory involvement

Questions to ask your doctor

It's important to understand why an endoscopy is being done and what the results mean. Consider asking:

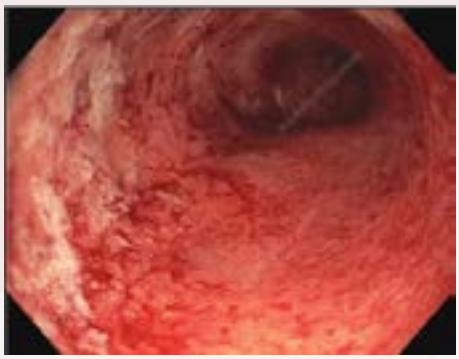
- Why are you recommending this procedure?
- Which parts of my gut will be examined?
- What should I expect during preparation and recovery?
- Will I need sedation and why?
- How long will the procedure take?
- When and how will I receive my results?
- What happens next if I am diagnosed with IBD?

Understanding your results

After your **endoscopy**, your doctor will discuss what was found. Common findings include **inflammation** and IBD **lesions**.[1,28] The nature of these helps determine your diagnosis and treatment plan.[25] **The images below are examples of how CD and UC can appear during endoscopy compared to a healthy gut**. Your doctor may show you similar images when explaining your results. Plain language explanations or written summaries can be helpful to review at home.

Visual aids

Endoscope view of a healthy colon.



Endoscope view of a colon with CD showing inflammatory polyps (red swellings) and ulceration (white areas).

Endoscope view of ulcerative colitis showing inflammation and ulceration.

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3.2

Ongoing disease management

Once diagnosed with IBD, the focus shifts to managing symptoms and monitoring.[37] This stage is about understanding disease behaviour, what symptoms mean, and how **endoscopy** guides treatment.[26,37,38]

What to expect

IBD symptoms vary over time, with periods of **flare-up** and **remission**.[13,29] Your doctor will use clinical assessments, endoscopy, and laboratory tests to monitor **disease activity** and adjust your treatment plan as needed.[38] Adjusting treatment over time is a normal part of IBD management and helps keep the disease under control.[26]

What your doctor is looking for

They're looking for changes in the signs of **inflammation** and damage (**lesions**) in response to treatment and for the early signs of longer-term **remission**.[3,26]

Key terms

Short-term and intermediate clinical targets

Medical term	Definition	Alternative terms
Symptomatic response	Symptomatic response is an early improvement in disease symptoms after starting treatment.[26,29] It is often the first sign of relief, when the most disruptive symptoms, such as abdominal pain or frequent trips to the bathroom, begin to ease.[20,25,27,29] It gives doctors an idea of how well the treatment might work in the long term.[26,29]	• Clinical response • Partial remission • Symptomatic improvement • Positive response to therapy
Symptomatic remission	Symptomatic remission is when symptoms disappear completely.[39] It indicates that symptoms are well managed by treatment, but the underlying disease can still be active.[26]	• Clinical remission • Symptom-free state
Biomarker remission	Biomarker remission is when **inflammatory biomarkers** associated with IBD have returned to normal levels, indicating the absence of inflammatory activity in the bowel.[5]	• Biochemical remission • Biomarker normalisation • Normalised inflammatory markers

Questions to ask your doctor

To stay involved in your ongoing care, consider asking:

- How is my disease activity being monitored?
- What do my results mean for my symptoms?
- How will my treatment be adjusted if my symptoms change or based on the results of my endoscopy?
- What should I do if I experience a flare-up or new symptoms?
- Are there lifestyle changes or resources that could help manage my symptoms?

Understanding your results

Endoscopy and other tests (like **inflammatory biomarkers**) help track disease activity and guide ongoing treatment decisions.[26] Your doctor may refer to clinical targets or **endoscopic scores** when discussing your results.[10,28] Plain language summaries or visual aids can help support your understanding.[6] Disease management is an ongoing process, and regular communication with your doctor can help you feel supported.[40,41]

3.3 Long-term remission

Beyond diagnosis and ongoing management, the focus of IBD care shifts to long-term remission (healing) and maintaining **symptomatic remission**.[5,26,39] **Endoscopic remission**, the visible healing of your **gut** seen during **endoscopy**,[24,42] is a key goal for improving quality of life and reducing the risk of complications.[3]

What to expect

Long-term management of IBD is about more than just controlling symptoms.[5] Your doctor will use **endoscopy** and other tests to monitor the health of your **gut** over time, aiming for sustained remission and prevention of **flare-ups**.[24,25]

What your doctor is looking for

Even without any symptoms, your doctor will look for signs that **inflammation** is controlled, damage (**lesions**) is improving, and that the **bowel** is healing.[1,20]

Key terms

Long-term clinical targets

Medical term	Definition	Alternative terms
Endoscopic response	Endoscopic response is when **inflammation** or **lesions** seen during an endoscopy have improved, without necessarily achieving the ultimate goal of complete **endoscopic remission**.[24] It shows treatment is working beyond just reducing symptoms.[24]	• Partial mucosal healing • Endoscopic improvement • Visual mucosal response
Endoscopic remission	Endoscopic remission is healing of the inner lining (**mucosa**) of the **gut**.[24,42] During an **endoscopy**, doctors see no **inflammation** or **lesions**.[1,20] It's a key long-term treatment goal because it's linked with **symptomatic remission**, reduced risk of complications, and improved quality of life.[3,5,39]	• Endoscopic healing • Mucosal healing • Visual mucosal healing
Normalised quality of life	Normalised quality of life refers to improving an IBD patient's health-related quality of life (HRQoL) so that they are able to live well and function day to day despite having a chronic condition.[5,26,43] This includes restoration of physical, psychological, social, and functional well-being, resulting in minimal impact on daily life.[26,43]	• Quality of life restoration • Recovery of quality of life • Normalised HRQoL

Colorectal cancer

Medical term	Definition	Alternative terms
Colorectal cancer surveillance	**Colorectal cancer** surveillance refers to regular **endoscopy** examinations to detect precancerous changes or early cancer.[4] Patients with long-standing IBD have a higher risk of developing colorectal cancer and surveillance allows timely treatment.[4,44]	• Colorectal cancer screening • Colonic dysplasia surveillance • IBD-related cancer monitoring

Questions to ask your doctor

It's important to have clear communication about your long-term treatment plan. Consider asking:

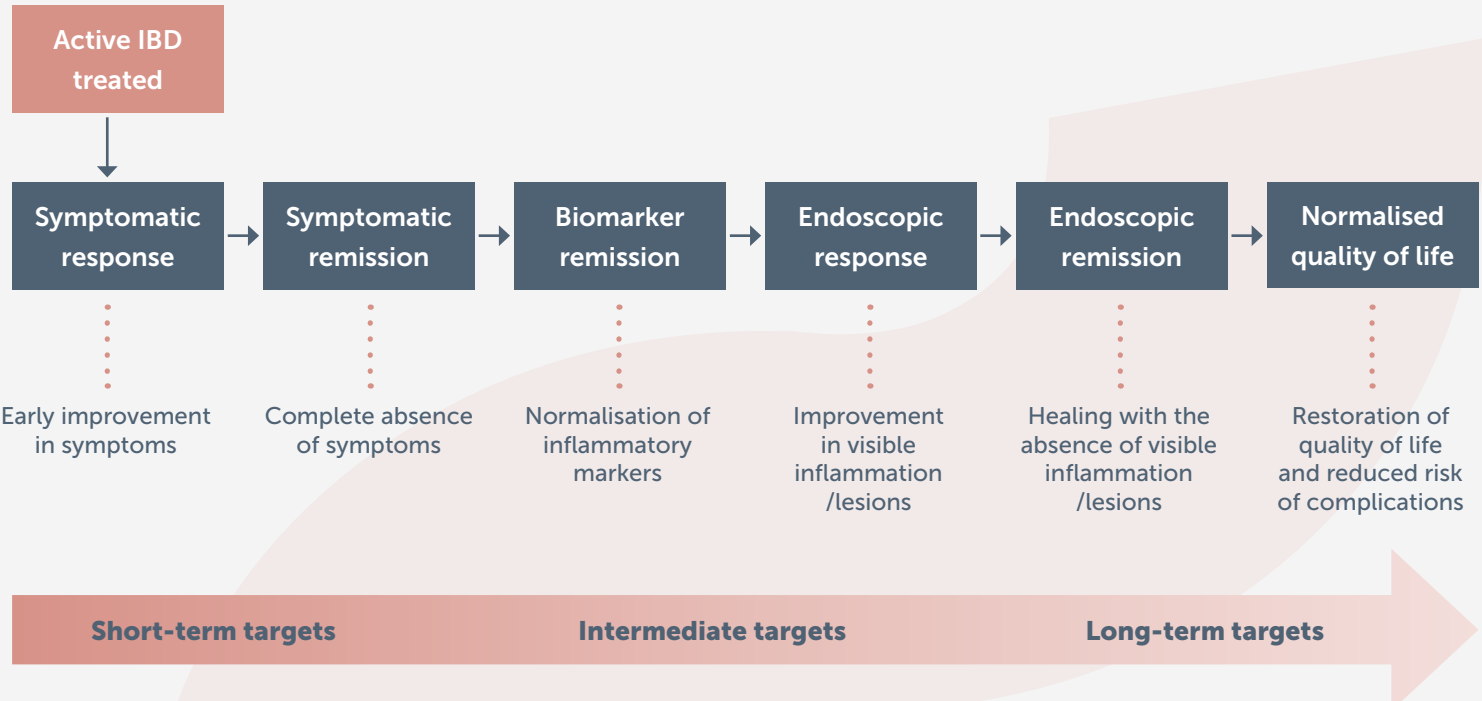
- What does endoscopic remission mean for my treatment and future health?
- How will my progress be monitored?
- What are my long-term goals/targets, and how do we measure them?
- How often will I need follow-up endoscopies?
- What can I do to support long-term remission and reduce my risk of complications?

Understanding your results

Endoscopic remission is a sign that treatment is working well, and that your gut is recovering.[3] Your doctor may refer to different types of **remission** and clinical targets when explaining your results.[5,26] **The visual aid below shows the different clinical targets associated with IBD and how they can evolve over time**. Plain language summaries or visual aids can support your understanding.

Long-term remission is a journey. Regular monitoring, open communication, and understanding your results will help you stay on track and maintain your health and well-being.[26,40,41]

Visual aid[45]



04

Glossary of terms

Glossary of terms		
Medical term	**Definition**	**Alternative terms**
Anus	The anus is the opening at the end of the **gut** where stool leaves the body.[14, 19] In IBD, this area can sometimes be affected, particularly in **CD**, and may cause symptoms such as pain, soreness, or bleeding, and complications like perianal **fistulas**.[41,46]	• Anal orifice • Bottom opening
Biopsy	A biopsy is a small sample of tissue removed from the body for examination, usually under a microscope.[13] They are taken during **endoscopy** to support diagnosis and distinguish between **UC** and **CD**.[13,20] Biopsies can also be used to detect precancerous changes early, enabling timely **colorectal cancer** treatment.[4,20,44]	• Tissue sample • Specimen collection • Histological sampling
Bowel	The bowel consists of the small and large intestines.[13,16] It absorbs nutrients and water, then eliminates stool from the body.[13,16] **UC** affects the large intestine (**colon** and **rectum**),[13] and **CD** can affect both the small (in particular, the terminal ileum) and large intestine.[13]	• Intestines
Colitis	Colitis is **inflammation** of the **colon**, specifically its inner lining (**mucosa**).[13,20,23,37] Colitis is not a single disease but a term for several conditions, including **UC** and **CD**.[47]	• Colon inflammation • Large bowel inflammation • Lower GI inflammation
Colon	The colon is the longest part of the large intestine.[13,17] It absorbs water and nutrients from food to form stool.[13] It's often the main site for IBD.[20] **UC** affects the colon and **rectum**, and **CD** affects the colon and other parts of the **gut**.[13,36]	• Large bowel • Large intestine • Lower GI tract
Colonoscopy	A colonoscopy is an endoscopy that examines the inside of the **colon**, terminal ileum, and **rectum**.[7,13] It's used to diagnose IBD,[28] distinguish between **CD** and **UC**,[20,28] monitor endoscopic **disease activity** and healing, and screen for the signs of **colorectal cancer**.[4,20]	• Colonic endoscopy • Large bowel endoscopy • Lower gastrointestinal (GI) endoscopy • Flexible colonoscopy • Ileocolonoscopy
Colorectal cancer	Colorectal cancer is cancer found in the large **bowel**, including the **colon** and **rectum**.[44] The chronic **inflammation** associated with IBD increases the risk of colorectal cancer.[20] Regular **endoscopies** and **biopsies** help doctors monitor the bowel over time.[1,20] In some cases, a technique called chromoendoscopy may be used. This involves spraying dyes onto the lining of the bowel during an endoscopy or using enhanced virtual imaging to help doctors spot **polyps** or early changes in cells, including signs of pre-cancer or early-stage cancer.[1,13,48]	• Bowel cancer • Colon cancer • Rectal cancer • CRC

Glossary of terms continued

Medical term	Definition	Alternative terms
Endoscopic scores	Endoscopic scores are standardised measures used to assess endoscopic **disease activity** observed during **endoscopy**.[10] They support monitoring, guide treatment decisions and help predict prognosis.[10,49]	• Endoscopic index • Endoscopic classification
Endoscopy	Endoscopy is the general term for medical procedures that use a thin, flexible tube with a camera and light (called an endoscope) to examine the inside of the **gut**.[2] The main types of endoscopies in IBD include: • **Colonoscopy** – examines the **colon**, terminal ileum and **rectum**.[7,13] • **Sigmoidoscopy** – examines the **rectum** and lower part of the **colon** called the sigmoid colon.[11,13] • **Gastroscopy** – examines the upper **gut** (oesophagus and stomach) and the first part of the small intestine (duodenum).[8,13] Endoscopy plays a key role in the diagnosis, ongoing management, and treatment of IBD.[1] It allows doctors to look for signs of disease inside the **bowel** and can be used to take **biopsies** to support diagnosis and response to treatment.[1,10,21]	• Scope procedure • Endoscopic examination • Internal camera examination • GI endoscopy • Flexible endoscopy • Visual check
Erosions	Erosions are a type of **lesion** found in IBD, where there are small, shallow breaks in the inner lining (**mucosa**) of the gut due to damage caused by active **inflammation**.[13,20]	• Superficial erosion • Superficial mucosal damage • Mucosal break
Fistula	A fistula is an abnormal tunnel-like connection that forms between two parts of the body.[13] In IBD, this happens when chronic **inflammation** breaks through the bowel wall.[36] Fistulas are most common in **CD**, and perianal fistulas, which form around the **anus**, are the most common type.[36]	• Fistulous tract • Abnormal passageway • Tunnel-like connection • Abnormal communication
Gut	The gut is a series of organs from the mouth to the **anus**, responsible for breaking down food, absorbing nutrients and water, and stool.[14] It includes the mouth, **oesophagus**, stomach, **bowel** (large and small intestine), and anus.[14]	• Gastrointestinal (GI) tract • Digestive tract • Alimentary canal
Gastroscopy	Gastroscopy is an **endoscopy** that examines the upper **gut** including the **oesophagus**, stomach, and the first part of the small intestine (duodenum).[8] It's used to diagnose **CD** in the upper gut,[10,13] monitor **disease activity**, and find the cause of symptoms like difficulty swallowing.[1,8]	• Upper GI endoscopy • Oesophago-gastro-duodenoscopy (OGD) • Upper GI scope
Histological remission	Histological remission is when **biopsies** show no **inflammation** under a microscope.[22,23] It looks at cell-level changes, such as absence of inflammatory immune cells and signs of cell repair.[22,23] It is known to be important in **UC**, but its role in **CD** is less certain.[22,23]	• Histological healing • Microscopic healing • Cell-level healing
Inflammatory markers	Inflammatory markers are biomarkers measured in blood, stool, or other body fluids that reflect the degree of **inflammation** in the body.[26,37] They are produced in response to injury, infection, or chronic inflammatory conditions.[37,50]	• Inflammatory biomarkers • Inflammation indicators • Inflammation tests

Glossary of terms continued

Medical term	Definition	Alternative terms
Mucosa	The mucosa is the innermost layer (lining) of the intestinal wall.[32] It secretes mucus and proteins, protecting against infections and mechanical damage.[32] In IBD, the mucosal barrier is damaged, allowing gut bacteria to trigger a chronic immune response, resulting in **inflammation** and **lesions**.[20,32]	• Mucosal lining • Intestinal mucosa • Mucous membrane • Gut lining
Mucosal friability	Mucosal friability occurs when the inner lining (**mucosa**) of the **bowel** becomes fragile and breaks down easily, leading to spontaneous bleeding.[51] It's a sign of active **inflammation** and indicates that the bowel wall is weakened and prone to damage.[51]	• Fragile mucosa • Fragile bowel lining
Oesophagus	The oesophagus is a tube connecting the throat to the stomach.[14] It transports food and liquids from the mouth to the stomach.[14] Oesophageal Crohn's disease is a rare severe form of **CD** with symptoms like reflux and difficulty swallowing.[52]	• Esophagus (US spelling) • Gullet • Food pipe • Upper GI tract
Polyp	A polyp is an abnormal growth that sticks out from the inner lining (**mucosa**) of the **bowel**.[13] There are two main types linked to IBD: • Inflammatory polyps, which form as the **mucosa** heals after repeated ulcers.[1] • Adenomatous polyps, which can become precancerous or malignant over time, potentially leading to **colorectal cancer**.[53] Most polyps don't cause any symptoms, so regular screening (using surveillance endoscopies) is important to monitor and remove them if needed.[53]	• Mucosal growth • Mucosal nodule • Adenoma • Small lump
Rectum	The rectum serves as a storage site for stool before defecation.[18] It's a key site for IBD, particularly **UC**, which always involves the rectum.[13] It can also be a site for **CD**.[13]	• Rectal segment
Sigmoidoscopy	A sigmoidoscopy is an endoscopy used to examine the **rectum** and lower part of the **colon** called the sigmoid colon.[13] It's used to diagnose and monitor **UC** and **CD**.[28]	• Flexible sigmoidoscopy • Sigmoid colon endoscopy • Sigmoid scope • Proctosigmoidoscopy
Stricture	A stricture is an abnormal narrowing of a section of the **bowel**.[13] It happens when chronic **inflammation** leads to scar tissue, which makes the bowel wall stiff and tight.[13] Strictures can partially or completely block the movement of food and waste through the **gut**, causing symptoms such as stomach pain or being unable to pass stool.[20,36]	• Stenosis • Bowel constriction • Bowel narrowing • Intestinal blockage • Bowel obstruction
Transmural remission	Transmural remission means the entire thickness of the bowel wall, not just the inner lining (**mucosa**), has healed and shows no **inflammation**.[5] It's especially important in **CD**, where inflammation can affect the entire bowel wall.[13,26]	• Transmural healing • Bowel wall healing
Ulcers	Ulcers are open sores that form on the inner lining (**mucosa**) of the **gut** due to chronic **inflammation**.[13,27] They happen when the inflammation breaks down the surface layer, leaving raw, exposed areas that can bleed and cause pain.[27] Ulcers are a common sign of active disease in **UC** and **CD**, but their location and depth can differ between the two conditions.[35,54]	• Sores • Ulcerations • Erosions • Mucosal breaks

Let's Talk Endoscopy was created in collaboration with a group of healthcare professionals, including gastroenterologists and IBD nurses, who generously shared their expertise throughout the development process. Their insights and content review were instrumental in shaping the content, ensuring the language, structure and explanations reflect routine clinical practice and address the real-world needs of people living with IBD. This group includes: Dr Badr Al Bawardy (Gastroenterologist, Saudi Arabia); Professor Alessandro Armuzzi (Gastroenterologist, Italy); Pearl Avery (IBD Nurse, UK); Professor Raf Bisschops (Gastroenterologist, Belgium); Dr Marietta Iacucci (Gastroenterologist, UK); Susanna Jäghult (IBD Nurse, Sweden); Simona Radice (IBD Nurse, Italy); Professor Alessandro Repici (Gastroenterologist, Italy); Catherine Walsh (IBD Nurse, Ireland).

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