ENGAGE-IBD

Your guide to engage in living well with Crohn's disease and Ulcerative Colitis

A patient-friendly resource to help you take control of your condition, build confidence, and live fully—with support every step of the way.

Created as part of the EU HORIZON HLTH-2022-STAYHLTH-02-01 miGut-Health to support patient engagement in IBD care.

Funded by the European Union

ABOUT THIS GUIDE

Living with **Crohn's disease** or **Ulcerative Colitis** often means adjusting how you manage your health, emotions, and everyday choices. There's no one-size-fits-all solution—but this guide is here to help you **understand** your condition, **build confidence**, and take **practical steps** toward living well with IBD.

This guide was developed together with people living with IBD, healthcare professionals, and experts in patient engagement as part of the miGut-Health project funded by the European Union. The ENGAGE-IBD guide is built on a health engagement framework that recognizes you as an **active partner** in your care. It encourages shared decision-making, self-awareness, and long-term planning to support well-being in a way that respects your values and goals.

To ensure the guide remains broadly applicable and does not overwhelm readers, topics that are highly individualized or specialized —such as pregnancy, sexuality, surgical interventions, or colostomy care—are not covered. However, we recognize that these issues may be important to you. If you need support or information on these specific areas, we encourage you to speak directly with **your IBD care team**, who can provide personalized guidance or direct you to trustworthy, specialized resources. You will also find a list of recommended references and resources on these topics at the end of this guide.

This guide does not replace medical advice. Always speak to your IBD team before making decisions about your treatment, diet, or care plan.

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Contents

Use this guide however works best for you. You can read it from start to finish or jump to the section that fits your needs right now.

ENGAGE-IBD
Introduction

Are you **dealing with IBD**?-Welcome to your ENGAGE-IBD guide

Having a diagnosis of Crohn's disease or Ulcerative Colitis-together called Inflammatory Bowel Diseases (IBD)-can feel overwhelming. It's completely natural to have a lot of questions and concerns. Living with a lifelong condition can be challenging, but you're not alone. It's okay to feel uncertain right now: **we're here to help you feel more in control.**

How to take control of your IBD

This booklet offers **clear information and simple, practical advice** to help you manage your daily life with IBD. It's been designed to help you feel **more confident and involved in your care:** not just following medical advice but actively making choices that fit your needs and goals.

To support you, we've created an easy-to-follow roadmap called **ENGAGE-IBD:** a **step-by-step approach** to living well with IBD.

E **Educate yourself about IBD**
Learn more about IBD so you feel **informed** and **prepared**

N **Navigate healthcare resources**
Find your way through the **healthcare system** and know who to **ask for help**

G **Gather insights from your symptoms**
Pay attention to how your body **feels** and notice changes in your **symptoms**

A **Adhere to treatment plans**
Stick with your treatment plan, even when it's not easy

G **Get active in decision-making**
Speak up and **share** your preferences when making choices with your care team

E **Enhance your emotional well-being**
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I **Implement a balanced diet**
Make **food choices** that work for you and your gut

B **Build a support network**
Reach out to people who can **support** and **understand** you

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ENGAGE-IBD Introduction

ENGAGE-IBD is built around the **real-life challenges** of living with Crohn's disease or Ulcerative Colitis. It gives you tools to understand your illness, follow your treatment, listen to your body, and get the right help when you need it.

The **sooner** IBD is detected and treated, the better. Getting inflammation under control early can protect your gut, prevent complications, and give you the best chance at long-term well-being. **Don't wait for symptoms to get worse**—stay connected with your care team and take action early.

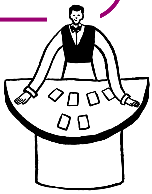
By **learning more about IBD and how to manage it**, you can feel more confident and supported. You'll also be better prepared to talk with your care team, make informed choices, and take small steps that improve your everyday well-being.

ENGAGE-IBD

Educate yourself about IBD

Why **learning about IBD** matters

Understanding IBD is one of the best ways to care for yourself. When you know **what's happening in your body**, you're more prepared to manage symptoms, make informed choices, and cope with the ups and downs of your condition. It can also ease anxiety and help you feel more confident during doctor visits.



Let's go over **the basics:**

IBD stands for Crohn's disease (CD) and Ulcerative Colitis (UC). Both are chronic conditions that cause long-term inflammation in the digestive tract.

Crohn's disease can affect any part of your gut, from your mouth to your anus. It often targets the **ileum** (the last part of the small intestine) or the colon, and the inflammation can spread deep into the bowel wall.

Ulcerative Colitis only affects the large intestine (colon and rectum) and usually involves just the inner lining of the bowel.

When parts of your bowel are inflamed, it can be harder for your body to **digest food and absorb nutrients**, which can affect your weight, energy levels, and overall health.

To learn more about IBD and the differences between Crohn's disease and Ulcerative Colitis, visit Crohn's & Colitis UK's website for easy-to-understand, reliable information.

Sources: (Crohn's & Colitis UK)

- All About Crohn's and Colitis
- Crohn's Disease
- Ulcerative Colitis

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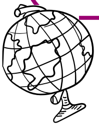
Educate yourself about IBD

IBD is a global health challenge…



More and more people around the world are being diagnosed with IBD. In Europe, over 3 million people live with it. In the past, countries like the UK and Scandinavia had the highest rates, but now, cases are also rising in southern and eastern Europe.

Key facts about IBD

An unhealthy gut can seriously affect your overall health and daily life. IBD affects not just your body but also your mental health, work, relationships, and education.

IBD doesn't just affect your gut—other parts of your body can be affected too. Symptoms may include frequent and urgent diarrhea (sometimes with blood and mucus), severe abdominal pain, extreme tiredness (fatigue), weight loss, loss of appetite, arthralgia (joint pain), and mouth ulcers.

IBD follows a pattern of ups and downs, with phases of active disease (flare-ups) and remission. IBD often comes and goes, with periods when the disease is active—called flare-ups—and times when symptoms ease or disappear, known as remission. During a flare-up, you may feel unwell and experience more intense symptoms. In remission, your condition is more stable, and you may feel better and more in control.

IBD has no known cure, but several treatments can help manage symptoms and improve quality of life. Medications and, in some cases, surgery are used to control inflammation and reduce flare-ups. Dietary therapy is also used in some cases—not only to help manage symptoms, but also to support good nutrition and promote gut healing.

What causes IBD?

The exact cause is still unknown, but it's likely due to a mix of factors:

Genetics

Changes in gut bacteria

Immune system dysfunction: The body mistakenly attacks its own gut.

Educate yourself about IBD

These, together with environmental factors, like food and stress, may trigger the conditions.

There's no clear proof that specific foods directly cause Crohn's disease or Ulcerative Colitis. However, some studies suggest that eating very few fruits and vegetables may increase the risk of Crohn's, and that a low vegetable intake might raise the risk of colitis in some people.

There is also some evidence that diets high in red meat or added sugar (like table sugar) could be linked to a higher risk. But there isn't enough evidence yet to say for certain whether food affects the risk.

Why education **matters**?

Educating yourself about IBD gives you the tools to handle the disease better and make informed choices. Here are a few reasons why knowledge is so necessary:

- **Understand your symptoms:** You'll learn which symptoms are common (like abdominal pain, diarrhea, fatigue) and what might trigger them. This understanding helps you prepare for daily life with IBD. *(Refer to:* **Gather insights from your symptoms.***)*

- **Work with your healthcare team:** Understanding how to access the right people/health professionals and actively participating in your treatment decisions empowers you to manage IBD more effectively. *(Refer to:* **Navigate healthcare resources** and **Get active in decision making.***)*

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Educate yourself about IBD

- **Get familiar with your treatment and diet:** Knowing how different treatments and dietary choices affect your IBD can help you stay committed to your care plan. *(Refer to:* **Adhere to treatment plans** and **Implement a balanced diet.***)*

- **Recognise emotional challenges:** IBD doesn't just affect your body; it can affect your mental and emotional well-being too. Understanding this side of IBD reminds you that you're not "just imagining it" - the emotional ups and downs are real and not your fault. *(Refer to:* **Enhance your emotional well-being.***)*

- **Let others help you:** Education is key—not just for you, but also for the people around you. When those in your life understand IBD better, they can support you in ways that truly make a difference. *(Refer to:* **Build a support network.***)*

- **Plan for the future:** Setting realistic short-& long-term goals—whether related to your health, lifestyle, or personal aspirations—can help you stay motivated and make proactive choices that improve your quality of life. *(Refer to:* **Define short- & long-term goals.***)*

Who is involved in the IBD care team?

Getting the best care for IBD means knowing who to turn to and how each professional supports your health.

Your care team may include specialists such as gastroenterologists, IBD nurses, dietitians, psychologists, and colorectal surgeons. The exact composition of the team may vary depending on the healthcare system in your country, but these professionals often work together to ensure you receive coordinated, patient-centered care.

Your IBD care team may look different depending on where you live, but here are some of the key roles and what they do:

Identifying the professionals who can help you

- **Gastroenterologists:** Doctors who specialize in digestive health. If you need help managing your treatment, monitoring your condition, or discussing new symptoms, contact your gastroenterologist.

- **IBD nurses:** Often act as care coordinators and key points of contact. If you need support with managing your care plan, medications, appointments, or test results, reach out to your IBD nurse.

Navigate healthcare resources

- **Psychologists:** Support you in coping with the emotional and mental challenges of living with IBD. If you're struggling with stress, anxiety, or the impact of IBD on your daily life, reach out to your psychologist.

- **Dietitians:** Assess your nutritional status and help you adjust your diet to support your gut health and overall well-being. If you need guidance on food choices or making changes in your diet, contact your dietitian.

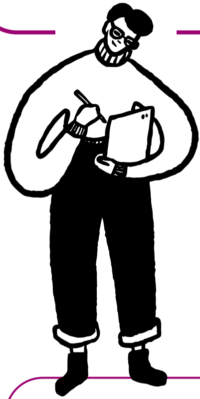
- **Colorectal surgeons:** Specialize in surgical treatment of the colon and rectum. If you need to discuss surgical options or address severe cases where medication isn't enough, contact your colorectal surgeon in collaboration with your gastroenterologist.

Tip

Keep a list of your care team with names, roles, and contact information. This helps you know who to reach out to when you need specific support.

Navigate healthcare resources

Accessing medical tests and treatments



IBD requires regular monitoring, and your doctor may recommend different tests to check your condition.

Understanding when and why these tests are needed can help you stay informed and actively participate in your care. If your doctor asks you to do a stool test, blood test, or imaging, knowing what they check for can help you prepare and understand the results.

- **Stool tests:** Look for infections and measure inflammation in your gut.

- **Blood tests:** Check for inflammation, low iron (anaemia), or vitamin deficiencies.

- **Endoscopy & colonoscopy:** These are procedures that allow doctors to look inside your digestive system to check for inflammation or damage. Colonoscopy is one type of endoscopy, used specifically to examine the large intestine (colon and rectum).

- **Imaging (MRI, CT, ultrasound):** Show detailed pictures of your intestines to spot problems.

Tip

Some patients may use home tests, like fecal calprotectin kits, to monitor gut inflammation between appointments. These tools can help you and your doctor detect changes early—even before symptoms appear—and support better disease control over time. Talk to your care team about whether home monitoring is right for you.

Navigate healthcare resources

Being organized can help you get the most out of your healthcare visits. *(Refer to:* **Gather insights from your symptoms.***)*

Managing appointments and medical records

- **Scheduling appointments:** Plan regular check-ups with your doctor and don't wait too long if symptoms change or get worse.

- **Getting prepared for the visits:** Write down questions and your timeline of symptoms and bring the list with you to your appointments.

- **Keeping medical records:** Save test results, treatment plans, and doctor's notes in one place, whether on paper or in a digital app.

- **Using patient portals:** Many hospitals and clinics offer online portals where you can access test results, prescriptions, and appointment details.

Tip

Bring a friend or family member to appointments if you need extra support or help remembering information.

ENGAGE-IBD
Gather insights from your symptoms

Symptoms **to watch for…**

Getting a diagnosis of IBD can take time because the symptoms are similar to those of other conditions, especially irritable bowel syndrome (IBS) or infections.

It's important to know that IBD and IBS are not the same: IBD involves **inflammation and damage in the gut**, while IBS **doesn't** and is generally less serious.

IBS is also much more common, which can make it harder for doctors to tell the two apart at first. That's why your doctor looks at the **whole picture**—your symptoms, medical history, and test results—to make sure you get the proper diagnosis.

IBD symptoms can be digestive or non-digestive, and they may differ depending on whether you have Crohn's disease or Ulcerative Colitis. Because Crohn's and colitis affect different areas of the gut, the pattern and severity of symptoms may differ between the two conditions:

- **Key digestive symptoms** include diarrhea (in Ulcerative Colitis, typically bloody and accompanied by rectal urgency and in Crohn's disease, stool is often mushy and not necessarily bloody), abdominal discomfort or pain, tenesmus (rectal cramping), pain or swelling around the anus, such as fistulas (small tunnels) or abscesses (infected pockets of pus).

- **Non-digestive symptoms** can affect other parts of the body—like joint pain, skin problems (red patches, painful bumps, or rashes), mouth ulcers, or eye inflammation (uveitis).

Men and women usually experience the same digestive and non-digestive symptoms, but women may sometimes notice changes in their menstrual cycle, such as missed periods (amenorrhea).

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Gather insights from your symptoms

Tip

Non-digestive symptoms may seem unrelated, but they could be connected to your IBD. That's why it's important to tell your gastroenterologist about any new or unusual symptoms, even if they don't involve your digestion. Your care team can help you understand whether they're linked to your condition and how to manage them.

Symptoms can also come and go; we call them "flare-ups" and "remission".

- **Flare-ups:** Symptoms worsen and affect daily activities.*

- **Remission:** Symptoms decrease or disappear for some time.

** Warning signs of a flare-up: Increased bowel movements, fatigue, pain, appetite changes.*

Tip

Identifying early flare-up signs can help you act quickly and adjust treatment.

Common symptoms	Crohn's disease	Ulcerative Colitis
Abdominal pain	++++	+++
Diarrhea	+++	++++
Rectal bleeding	++	++++
Weight loss	+++	++
Fatigue	++++	++++
Loss of appetite	++	+
Fever	++	+

(++++) = very typical, (+++) = common, (++) = occurs, (+) = uncommon

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Gather insights from your symptoms

Signs of inflammation	Crohn's disease	Ulcerative Colitis
Anal fistulas, abscesses	++	
Liver disease	+	++
Joint pain (arthralgia)	+++	+++
Skin problems	+	+
Eye inflammation (uveitis)	+	+
Mouth ulcers	+	

(++++) = very typical, (+++) = common, (++) = occurs, (+) = uncommon

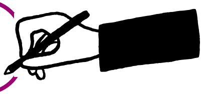
To learn more about the symptoms of Crohn's disease and Ulcerative Colitis, visit Crohn's & Colitis UK's information hub for detailed guidance.

Source:

Crohn's & Colitis UK.
All About Crohn's and Colitis.

Gather insights from your symptoms

How can you **track** your symptoms?



Keeping track of your symptoms can make a big difference in managing IBD. It allows you and your doctor to notice patterns, understand what might trigger symptoms—like certain foods, stress, or medications—and catch early signs of a flare-up.

- Keep a **journal** or use a **symptom-tracking app** to log daily symptoms.
- Track **frequency** and **severity** of symptoms (e.g., mild, moderate, severe).
- Record **details** that worsen your symptoms (e.g., food, stress, medication changes).
- Note how symptoms affect your **daily life** (work, sleep, energy levels).

Tip

While tracking symptoms daily may not be helpful or necessary for everyone, many people find that using an app (like MyIBD Care or GI Monitor)—even just during flare-ups or treatment changes—can provide useful insights and improve communication with their care team.

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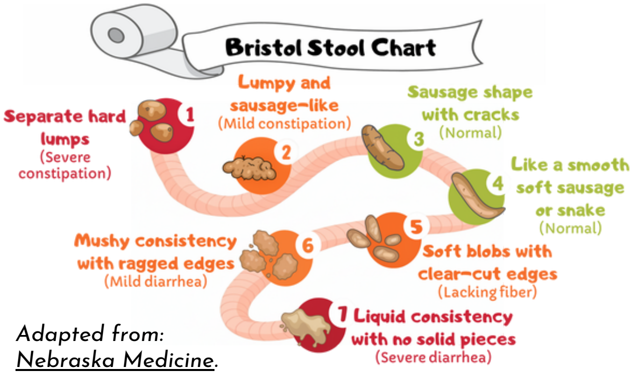
Gather insights from your symptoms

How to describe your symptoms?

Sometimes, it can be hard to explain how you're feeling, and finding the right words to describe your symptoms isn't always easy. Here are some tips to help you talk about your symptoms more clearly:



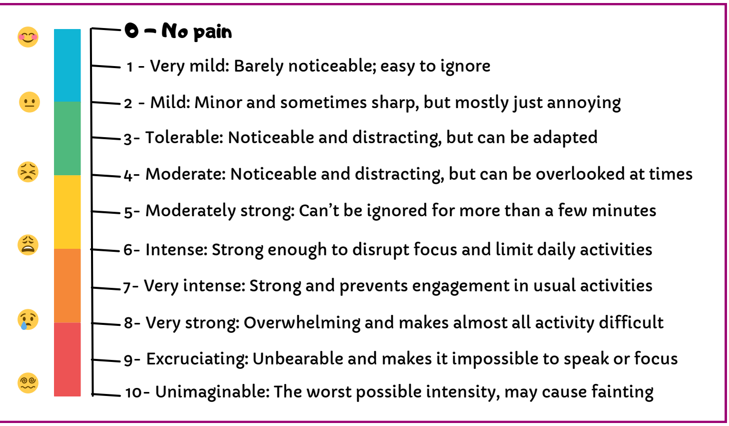
Adapted from: Nebraska Medicine.

Talking about **bowel movement...**

- The Bristol Stool Chart helps you describe the shape and texture of your stool, making it easier to talk about with your doctor.

Talking about **pain...**

- Everyone experiences pain differently. Using a pain scale can help your doctor understand how severe your pain is.



0 – No pain
1 - Very mild: Barely noticeable; easy to ignore
2 - Mild: Minor and sometimes sharp, but mostly just annoying
3- Tolerable: Noticeable and distracting, but can be adapted
4- Moderate: Noticeable and distracting, but can be overlooked at times
5- Moderately strong: Can't be ignored for more than a few minutes
6- Intense: Strong enough to disrupt focus and limit daily activities
7- Very intense: Strong and prevents engagement in usual activities
8- Very strong: Overwhelming and makes almost all activity difficult
9- Excruciating: Unbearable and makes it impossible to speak or focus
10- Unimaginable: The worst possible intensity, may cause fainting

Tip

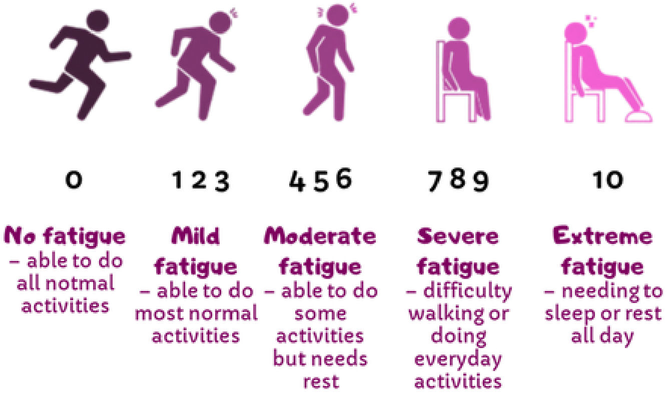
Pain can be hard to describe, but using words like aching, burning, sharp, stabbing, or blunt can help your doctor understand what you're feeling and find the best way to manage it.

Talking about **fatigue**...

- Like pain, fatigue can be difficult to describe. Thinking about how it impacts your daily activities can help you explain it better.

Tip

Fatigue can feel different for everyone. Using words like brain fog, heaviness, extreme exhaustion, or feeling shattered can help you describe it more clearly.



0	1 2 3	4 5 6	7 8 9	10
No fatigue – able to do all notmal activities	**Mild fatigue** – able to do most normal activities	**Moderate fatigue** – able to do some activities but needs rest	**Severe fatigue** – difficulty walking or doing everyday activities	**Extreme fatigue** – needing to sleep or rest all day

Adapted from: Voice Ability

Want to understand medical terms better?
For an extensive glossary of IBD-related words, visit Crohn's & Colitis UK's medical glossary.

ENGAGE-IBD

Adhere to treatment plans

Why sticking to your treatment plan matters?

Adhering to your treatment helps prevent flare-ups, manage symptoms, and reduce complications. Stopping and skipping medication without medical advice can lead to worsened symptoms or hospitalization. IBD is a long-term condition —even when symptoms improve, inflammation can still be active beneath the surface.

Adherence is a journey

Sticking to your treatment plan is not about being perfect. It's about building consistency, even when life gets in the way.

Achieving and maintaining adherence is a process you build over time, not a one-time action. It involves navigating different stages and overcoming potential barriers along the way, often requiring ongoing support and adjustments.

Understanding your "why" can keep you motivated. Remind yourself of the bigger picture—feeling better, staying active, or reaching personal goals can help you stick with treatment, even on tough days.

- **Start:** Begin with a plan—understand your treatment, ask questions, and commit to your health.

- **Tough moments:** You may need to face challenges like side effects, low motivation, or uncertainty—it's normal.

- **Adjust:** Small tweaks—like switching medication formats, setting reminders, or using a pillbox—can make it easier to stay on track.

- **Continue:** Keep going, even when it's hard. Staying consistent with your treatment takes patience and persistence —but every step counts.

Adhere to treatment plans

Remember: There is no one size fits-all!

Every person with IBD follows a unique treatment plan—tailored to their symptoms, disease course, and needs.

Some people take medication, follow specific diets, use supplements, attend regular check-ups, or include emotional support in their care.

These plans can change over time, depending on how you feel, how the condition progresses, and what matters most in your daily life.

Following your plan can feel complex or exhausting—and that's completely understandable.

Common challenges

Following your treatment plan isn't always easy. Many people with IBD face challenges that can get in the way of taking medication regularly. Life is unpredictable—you might feel motivated one day and discouraged the next.

But recognizing these ups and downs is the first step.

Talking to your healthcare team can help you find practical strategies that fit your life and make sticking to your plan easier. *(Refer to:* **Navigate healthcare resources.***)*

Some common reasons people struggle to stay on treatment include:

Feeling better and assuming meds are no longer needed

"I feel fine, so I don't need my medication."

Difficulty remembering doses or refills

"I forgot to take my meds."

Complex routines or changes in daily life

"With everything going on, it is hard to keep track of my treatment."

Concerns about side effects

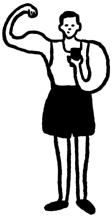
"I'm worried about side effects."

Adhere to treatment plans

Tips

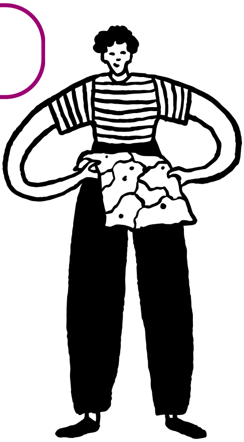
It's completely normal to have concerns—some side effects can feel discouraging. But don't stop treatment without talking to your doctor. Most side effects are manageable, and your care team can work with you to adjust your treatment or find ways to ease the discomfort.

You're not expected to handle everything alone. Bring up any concerns during appointments—even small ones. Managing treatment together with your care team helps you stay in control and feel supported.



Simple ways to **keep up** with your plan

- **Make it part of your routine:** Link your treatment to daily habits—like taking it with breakfast—so it feels natural, not like an extra task.

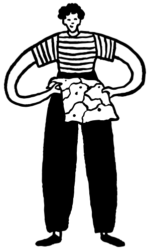


Adhere to treatment plans

- **Use reminders that fit your life:** Whether it's a phone alarm, pill organizer, or a fridge calendar, simple tools can help you stay on track—even on busy days.

- **Track how you feel:** Using a notebook or app to log symptoms, side effects, or questions can help you spot patterns and prepare for your next appointment.

- **Talk openly with your doctor:** If your treatment isn't working well in your life or causing side effects, your doctor can help adjust it to better fit your needs. *(Refer to:* **Navigate healthcare resources** *and* **Get active in decision making.***)*



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Get active in decision-making

Be your own advocate: Your voice makes a difference!

Being active in decision-making doesn't mean doing it all alone. It means being part of the team that shapes your care—bringing your experiences, preferences, and goals to the table.

You and your healthcare team are not on opposite sides—you're a team, working together to improve your well-being.

Managing IBD works best when your knowledge of daily life joins with your healthcare team's medical expertise. Your experience shows how IBD truly impacts you, and sharing this helps your team provide care that is more complete and personalized.

By speaking up about your needs and challenges, you strengthen the partnership with your doctors and care team, making decisions together that truly fit your life.

Start by sharing what matters to you

Being active doesn't mean you have to know all the answers or make decisions on your own. It means staying informed, speaking up about what's important to you, and making choices.

Being part of decisions means openly sharing what fits your life, such as how treatments affect your routine, concerns about side effects, or practical issues like work and family. At the same time, some options may have medical limits, and your doctors will guide you on what is safe and effective.

By combining your perspective with their expertise, decisions can be made together in a way that respects both your needs and the best medical evidence.

Tip

Start with your personal goals. What does "feeling well" mean to you? What would you like to be able to do more of in your daily life?

Get active in decision-making

Why being active makes a difference

There's no one-size-fits-all approach to Crohn's or colitis. When you're involved in shaping your treatment, it's more likely to match your lifestyle and feel manageable. People who actively participate in care often feel more confident, better understand their condition, and are more likely to stick with their treatment plan. (*Refer to:* **Adhere to treatment plans.**)

It can also help reduce anxiety, improve how you manage symptoms, and strengthen your relationship with your healthcare team.

Tip

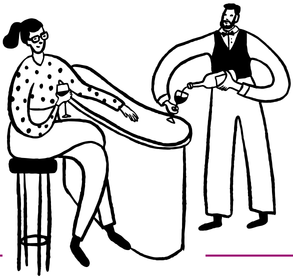
Being involved in decisions today lays the foundation for a more confident and empowered tomorrow. Over time, this shared approach leads to better health and a stronger sense of control.

The role of the IBD nurse

IBD nurses are often your first point of contact and can be strong advocates on your behalf. They can help you understand your options, talk through concerns, or bring up sensitive topics—like fatigue, pain, or sexual health—that might feel difficult to discuss. They also help coordinate your care, solve practical problems, and make sure your voice is heard. (*Refer to:* **Navigate healthcare resources.**)

Get active in decision-making

Shared Decision Making in managing IBD – and how it works



Shared Decision-Making is a process where you and your healthcare team make decisions together to choose the best care plan for you. It's not about agreeing with everything; it's about:

1. **Ask questions & stay informed:** Ask for detailed information about your treatment options—including the pros and cons, potential benefits, and any risks—so you can make choices that feel right for you.

2. **Share:** Talk openly about your goals, values, and preferences—and ask for support while reviewing your options. This helps your care team recommend what truly fits your life.

3. **Discuss and decide together:** Go over the options with your healthcare team and make a shared decision—one that's based on medical evidence and shaped by your personal needs and priorities.

4. **Follow through and stay connected:** Once you've made a decision, keep in touch with your healthcare team. Ask follow-up questions, share how things are going, and speak up if anything changes.

Get active in decision-making

Participate in shared decision making

Being open and honest with your healthcare provider is one of the most powerful ways to stay actively involved in your care. It's not always easy—but sharing your symptoms, concerns, preferences, and expectations helps your team understand what works best for you.

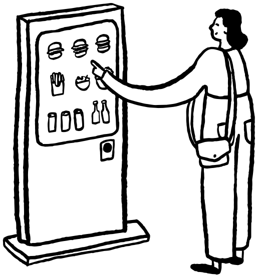
Keep notes between appointments. Write down how you've been feeling, any changes you've noticed, or side effects you want to talk about. These notes help guide the conversation.

Bring your questions. Write down anything you're unsure about—your treatment, tests, or next steps. Even a few notes can make it easier to speak up and stay focused.

Bring someone with you. A friend or family member can help you feel more confident, take notes, or ask questions on your behalf if needed.

Explore your options. There's rarely just one "right" choice. You and your provider can look at different options together and choose the one that best fits your goals and lifestyle.

How is treatment affecting your life? Side effects you're experiencing... What's difficult to follow or stick to? Your goals (e.g., work, family, travel) Concerns about long-term plans... What can you speak up about?



Enhance your emotional well-being

What is emotional well-being?

Living with IBD affects more than just your digestive system—it reaches into how you think, feel, and relate to others. **Emotional well-being** means having the resources to cope with stress, regulate emotions, feel connected, and maintain a sense of meaning and self-worth, even during difficult times.

Taking care of your mind is part of taking care of your IBD

It doesn't mean feeling positive all the time. It means **having the space to feel what you feel,** and the tools to navigate it. With a chronic illness, emotional well-being is not an extra—it's essential. Caring for your emotional well-being doesn't mean ignoring your struggles—it means facing them with support, honesty, and courage.

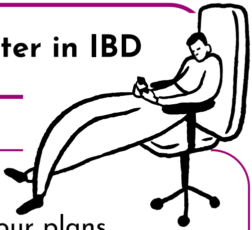
Even in hard times, **a hopeful outlook, a small act of self-care, or a moment of connection can make a real difference.** When you prioritize your emotional health, you're not just surviving IBD—you're learning how to live well with it.

Tip

Emotional well-being is not a destination—it's a daily practice. You don't have to do it perfectly. Just keep going, one small step at a time.

Managing Crohn's disease or Ulcerative Colitis means managing the **emotional side** of things too.

Why emotions matter in IBD



You might feel:

- Anxious about when the next flare-up will come.
- Frustrated when your body doesn't cooperate with your plans.
- Embarrassed or nervous in social settings—especially when access to a toilet feels uncertain.
- Sad or emotionally drained, especially if fatigue isolates you or your routines are disrupted.

Enhance your emotional well-being

And then there's something harder to talk about: **stigma**.

The invisible nature of IBD can lead others to underestimate what you're going through. You may feel misunderstood or judged—by strangers, colleagues, or even friends and family. This sense of being "on your own" can add another layer of emotional pain.

Please know: these feelings are valid. You're not overreacting—you're reacting to something real.

And most importantly, you don't have to go through it alone.

The **emotional-physical** connection: A real, evolving conversation

There is growing evidence that emotional distress—such as stress, anxiety, or depression—can influence how IBD behaves, potentially making symptoms worse or more noticeable.

Researchers call this the IBD-Stress Loop: when stress fuels symptoms, and symptoms increase stress.

While this loop is still being explored, what we do know is this: taking care of your emotional health can make managing your condition easier. Feeling emotionally supported helps you cope better, communicate more effectively, and stay engaged in your care.

Enhance your emotional well-being

Supporting your emotional well-being day by day

- **Talk it out:** Share your feelings with someone you trust. Speaking with a friend, partner, or professional can lift a heavy weight. If emotions feel persistent or overwhelming, **a psychologist experienced in chronic illness** can offer targeted support and therapeutic tools—not just general advice. *(Refer to:* **Navigate healthcare resources.***)*

- **Move gently:** Light physical activity—like walking, stretching, or gentle yoga—can release tension, improve your mood, and reconnect you with your body. Rest is important too. Emotional well-being includes knowing when to pause.

- **Practice self-kindness:** You won't feel the same every day—and that's okay. On the hard days, try to offer yourself the same compassion you'd give a friend. Your emotions are not a weakness—they are a sign of what matters to you.

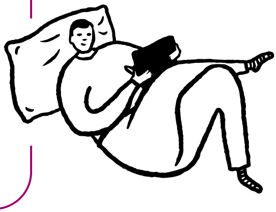
- **Do small things that bring you peace:**

Listen to music or a calming podcast.

Spend time in nature or take a short walk.

Write your thoughts in a journal.

Try something creative like drawing or crafting.



When emotions meet the plate…

Emotions don't just shape your mood—they can shape how and what you eat. Stress or sadness can reduce your appetite—or push you toward comfort foods. These are **normal responses**. Living with IBD can also create grief around food—especially when flare-ups force you to avoid things you used to enjoy.

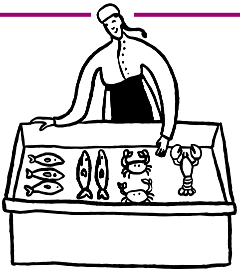
Food is emotional. And in IBD, that emotional connection is complicated. In the next section, we'll explore how to rebuild a healthy, compassionate relationship with food—one that supports both your gut and your emotional well-being.

If meals once brought comfort or joy, avoiding certain foods during flare-ups can feel like a real loss. This emotional connection to food is valid, and in the next section, we'll explore how to support both your gut and your emotional well-being through balanced eating. *(Refer to:* ***Implement a balanced diet.****)*

Implement a balanced diet

Why **diet matters** in managing IBD: Can food cure Crohn's or colitis?

Fuel your body, support your gut, and care for your well-being



Living with Crohn's disease or Ulcerative Colitis means your gut needs extra care—and so does your whole body. While **no specific food or diet can cure IBD**, good nutrition can support healing, reduce the risk of flare-ups, and help you feel more balanced and resilient.

You may come across "miracle diets" online or on social media, but there's **no strong evidence** that one diet works for everyone. That said, some people do benefit from **specific dietary approaches**—such as low-residue diets during flares, or tailored plans after surgery or when strictures (narrowed sections of the intestine that make it harder for food to pass through) are present.

Always **speak with your care team** before making big changes, so your diet remains safe, balanced, and right for your needs.

A healthy, balanced diet gives your body the fuel it needs to stay strong, manage inflammation, and recover more easily—especially after flare-ups or treatment.

**"You don't need a perfect diet.
You just need the one that works for you."**

What does "**balanced**" really mean?

A healthy diet includes a variety of foods that give you energy, support healing, and help your gut function at its best. While your diet may change during flares, the Eatwell Guide from Public Health England is a helpful reference for times when you're feeling well and able to eat a wider variety of foods.

ENGAGE-IBD

Implement a balanced diet

See the Eatwell Guide below for an overview of what a balanced diet looks like:

This guide reminds us to:

- Eat at least **five portions of fruit and vegetables** a day
- Choose **wholegrain or high-fiber** starchy foods
- Include **lean protein** sources like fish, eggs, beans, and pulses
- Use **unsaturated oils** in small amounts
- Drink 6–8 cups of **fluid** a day
- Limit foods **high in fat, salt, and sugar**

During a flare, some of these foods may be harder to tolerate. That's okay. The goal is not perfection, but balance over time.

For more detailed guidance on food and IBD, you can refer to the **Crohn's & Colitis UK** booklet Food: Your Guide. It offers practical, evidence-based information on nutrition and how to adapt your diet during different phases of the disease.

Source:

Crohn's & Colitis UK. Food: Your Guide

Implement a balanced diet

Personalising your plate

What works for one person may not work for another—and that's okay. Some foods may trigger symptoms during a flare but be well-tolerated later. The key is learning to listen to your body without fear or guilt.

If you're cutting out foods, do it with guidance. Avoid eliminating major food groups on your own, as this can lead to nutrient deficiencies, low energy, and even worsen symptoms over time. If you're unsure, ask your IBD nurse, doctor, or dietitian for support. *(Refer to:* **Navigate healthcare resources.***)*

When food feels like the enemy...

There may be times when eating feels stressful—when you fear that any bite could lead to pain or a flare. It's natural to become cautious. But skipping meals, over-restricting, or self-experimenting without support can do more harm than good.

Without enough nutrition, your body may not get what it needs to stay strong, leaving you tired, anxious, and physically drained. And here's something many people with IBD have shared: finding the right foods for your gut is a personal journey—and it often takes time. While some foods are widely known to be helpful or harmful, every gut is different. What bothers one person might be completely fine for another—and sometimes it even changes over time.

Track what works—for you

Understanding how your body responds to different foods can take time. One helpful strategy is to keep a simple **food and symptom diary**. Writing down what you eat and how you feel can reveal patterns that help you—and your care team—identify possible triggers or foods that support your well-being.

Implement a balanced diet

📘 *Use a daily diary like the one below to gently track your meals and any symptoms. This can be especially useful before appointments or when trying new foods.

Personal Food & Gut Journal: an example

Day:	**What I ate or drank**	**How did it make me feel? (e.g., comfort, pain, bloating, energy)**	**When did I notice a reaction (if any)?**
Breakfast	*Porridge with banana and almond milk*	*Felt light and settled, had energy all morning*	*No issues noticed*
Mid-morning snack	*Black tea and a rice cake with peanut butter*	*Satisfying; slight bloating after tea*	*30 mins after eating*
Lunch			
Mid-afternoon snack			
Dinner			
Other reflections	*Felt more tired today. Stressful meeting in the morning. Didn't sleep well last night.*		

Source:

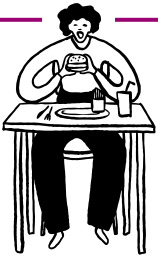
Adapted from Crohn's & Colitis UK.
Food: Your Guide

Implement a balanced diet

Feeling stressed? It might change **how you eat**

Along with flares or symptoms, stress can affect how you eat—and not always in predictable ways. During stressful times, you may lose your appetite or eat less than usual. But for many, stress triggers the urge to eat more or reach for comfort foods high in sugar or fat.

Recent data from miGut-Health research showed that stress doesn't just worsen symptoms—it can also disrupt eating patterns and influence food choices.



These patterns are closely tied to your emotional well-being. Recognizing the link is the first step *(Refer to:* **Enhance your emotional well-being***)* and it can help you take small, supportive steps to feel more balanced and in control.

Smart swaps to stay balanced when stress hits

Keep gut-friendly snacks on hand. Soft bananas, plain crackers, boiled potatoes—easy-to-digest choices can help when hunger hits.

Make a "safe food" list. Write down foods that usually feel good on your gut—refer to it when you're unsure.

Pause and check in. Before eating, ask yourself: am I physically hungry or feeling something else?

Eat small, regular meals. Waiting too long can lead to bigger hunger spikes; smaller, steady meals are easier on your gut.

Try non-food stress relievers. Calming activities, like movement, music, or journaling can help you manage emotions without turning to food. *(Refer to:* **Enhance your emotional well-being.***)*

Implement a balanced diet

Try **mindful eating**

Mindful eating helps you reconnect with your food and body. It's about slowing down, noticing how you feel, and eating in a way that supports your well-being. Here are 6 ways to practice it with IBD:

Mindless eating	Mindful eating
😕 Ignoring your body's signals and eating past full	😊 Noticing hunger and fullness cues—eating just enough
😟 Eating because of emotions (sadness, stress, boredom)	🌶️ Eating when your body needs fuel (not just emotions)
⏰ Eating at random times and places, often alone	📅 Creating a calm, regular mealtime routine
🍔 Choosing foods that comfort emotionally, not physically	🥬 Choosing foods that support your gut and overall health
📱 Eating while distracted (TV, phone, work)	🚫📱 Focusing only on your meal—no screens or distractions
🏃‍♂️ Treating meals as something to rush through	🍴 Slowing down and appreciating your food (its smell, taste, and how it makes you feel)

Tip

Mindful eating is not about getting it perfect—it's about building a more peaceful, supportive relationship with food, one bite at a time.

ENGAGE-IBD

Build a support network

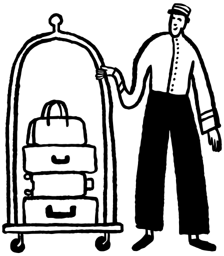
You don't have to do this **alone**

Living with IBD can sometimes feel lonely—but you're not alone. Connecting with people who truly understand what you're going through can make a big difference. Whether it's emotional encouragement, practical help, or just someone to check in on tough days, your support network can be a powerful part of your care.

Getting help is a **strength**, not a weakness

Asking for support isn't isn't a sign of failure —it's a step toward feeling more empowered.

The people around you can help lighten the load, both emotionally and physically. Your support network can offer encouragement, share ways to cope, and remind you that you're not going through this by yourself.



Tip

Seek out support that makes you feel heard, respected, and emotionally safe.

Family & friends

Living with IBD can affect how you relate to others—and sometimes people around you may not fully understand what you're going through. You might face:

- **Frustration** when your condition is invisible to others.
- **Guilt** for cancelling plans or needing help.
- Feeling **misunderstood** or **dismissed.**

Tips to build support

- **Talk openly** about what flare-ups feel like and what you need.
- Let loved ones know how they can **check in** or **offer help** (meals, errands, emotional support).
- Share simple resources to help them learn about IBD and how to support you, like the ***ENGAGE-IBD guide.***

Build a support network

Workplace support

IBD can create challenges at work, from managing fatigue to coping with symptoms during meetings.

Many patients report:

- **Worry** about stigma or not being taken seriously.
- **Difficulty** with rigid schedules or bathroom access.
- **Anxiety** about taking time off for appointments.

Tips to create a more supportive environment

- **Talk to someone you trust**—such as a manager or HR.
- **Discuss options** like flexible hours or remote work.
- **Clarify** the importance of restroom access and understanding during flares.

It's easy to feel isolated when your condition isn't visible.

Some people:

- **Don't know** anyone else with IBD.
- **Feel reluctant** to open up or fear being judged.
- **Struggle** to find relatable experiences in clinical settings.

IBD communities & support networks

Start with patient organisations.

Many offer trustworthy, condition-specific information and organize local or national events.

They can guide you to legal, nutritional, or psychological support.

Examples include IFCCA or IBD patient associations in your country.

Tips to find connection and strength

- Join support groups (online or in-person) for shared advice and empathy.
- Talk openly in safe, moderated spaces—hearing "me too" can be powerful.
- Use forums or apps that connect you with others navigating similar challenges.

ENGAGE-IBD

Build a support network

Tip

Look for IBD networks such as IFCCA–the International Federation of Crohn's & Ulcerative Colitis Associations–which connects national patient organizations across Europe. You can explore local and national partners to find community, support, and advocacy opportunities.

You can also ask your gastroenterologist, IBD nurse, or a local patient organization about peer support groups or patient ambassador programs in your region.

📖 *Source: IFCCA - About Us*

Emotional support matters... But, practical support helps too

Having someone to talk to–someone who really gets it–can ease emotional stress, reduce anxiety, and help you feel less isolated.

It could be a trusted friend, a family member, a mental health professional, or a fellow IBD patient in a support group. Sometimes, just having someone say "I understand" is enough to make a tough day feel manageable. *(Refer to:* ***Enhance your emotional well-being.****)*

Practical support means having people around you who can take action when you need help.

IBD isn't just about managing symptoms–it's also about keeping up with daily life, even when you're not at your best. This kind of support helps you stay on track with treatment and lowers your stress so you can focus on healing.

They can:

- Remind you to take your **medications** or go to **appointments.**
- Help preparing IBD-friendly **meals or snacks.**
- **Drive you** to the doctor or hospital.
- **Run errands** when you're tired or in pain.
- Help **clean or organize** your space if you're not feeling well.
- Join you at **appointments** for support.

Build a support network

Tip

Be specific when asking for help—say things like "Would you mind coming with me to..." so people know exactly how they can support you.

Asking for support starts with a conversation

People often want to support you, but they might not know how. That's why speaking openly about your needs is so important: it helps others support you in ways that are truly helpful, not just well-intended.

Let people know how IBD affects your life—like how fatigue can hit suddenly, or how stress can trigger symptoms. These are things others might not see, but they shape your everyday experience. When people understand more, they can show up for you in better ways.

At the same time, setting boundaries is just as important. You're allowed to protect your energy, say no to unwanted advice, or choose what (and when) to share.

Examples of what you can say

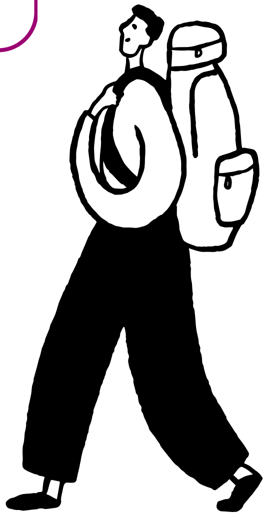
- "It would really help if you could remind me about my appointment next week."
- "I appreciate that you're checking in, but I'm not ready to talk about it today."
- "Thanks for the advice, but I just need someone to listen right now."

Boundaries aren't selfish—they're **self-care**. You can be open and **protect your space.**

For tips on how to talk openly about IBD with loved ones, friends, or employers, check out the Talking Toolkit from Crohn's & Colitis UK, with practical advice on how to feel confident when discussing your condition:

Define short- & long-term goals

Setting **realistic goals** to help manage IBD



Living with IBD isn't just about managing symptoms—it's also about building a life that feels meaningful to you. Setting clear, realistic goals can give you a sense of direction and help you focus on what matters most.

Your goals can change over time, and that's okay. Life brings different phases and challenges, like starting a new job, returning to school or university, preparing for travel or long trips, relocating or changing living arrangements, facing financial stress or job loss, pregnancy, menopause, undergoing surgery, hospitalization, or aging.

What matters is adjusting your goals as your needs evolve and taking it one step at a time.

Living with IBD isn't just about managing symptoms—it's also about building a life that feels meaningful to you. Setting clear, realistic goals can give you a sense of direction and help you focus on what matters most.

For guidance on navigating big life changes with IBD—like starting a new job, going back to school, traveling, surgery, pregnancy, sexuality, or adjusting to aging—explore Crohn's & Colitis UK's resources on living with Crohn's or Colitis.

Source:
Crohn's & Colitis UK.
Living with Crohn's or Colitis.

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Define short- & long-term goals

Goals can be as unique as your journey

Your goals will reflect your personal health situation—like the type and severity of your disease, your age, symptoms, other conditions, and your emotional or social needs. You might focus on one goal at a time, set a few together, or revise them as your life circumstances change.

A useful approach for goal setting - SMARTER goals

SMARTER goal setting means turning big ideas into smaller, doable steps that feel realistic and motivating. Each letter in "SMARTER" offers a simple tip to help you define goals that truly support your health and daily life with IBD.

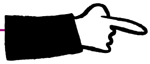
- **S Specific:** Be clear about what you want. Break big goals into smaller steps—for instance, "I want to walk 60 minutes a week."
- **M Measurable:** Make sure you can track your progress. For example, "I'll walk 20 minutes, 3 times a week."
- **A Attainable:** Choose a goal that fits your health and lifestyle. If mornings are hard, plan walks during lunch with shoes kept at work.
- **R Relevant:** Pick a goal that matters to you, not what others think you should do. For example, choose to do yoga at home if that feels better for your body than going to the gym.
- **T Time-bound:** Set a timeframe—for example, start next week and aim to increase your goal after two months.
- **E Evaluate:** Check how it's going. Use a calendar or app to track progress and adjust as needed.
- **R Reward:** Celebrate milestones. After a few weeks, treat yourself—like a new playlist, a dinner out, or comfy workout gear.

ENGAGE-IBD

Define short- & long-term goals

Examples of goals

- **Physical goals:** Reduce or manage symptoms like abdominal pain or frequent bowel movements.
- **Mental health goals:** Decrease stress, frustration, and anxiety, improve confidence, or experience better peace of mind.
- **Life goals:** Return to work, school, or volunteer activities, start a family, gain self-care skills, attend a social event, or eat at a restaurant.
- **Medical goals:** Improve lab results,reduce inflammation.



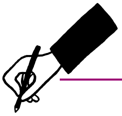
Step 1: Prioritize what matters to you

- Start by **identifying an area** of your life or health you'd like to improve. This helps you focus on personally meaningful goals.

What matters most to you right now?

☐ Staying in remission
☐ Managing stress
☐ Eating better
☐ Improving energy
☐ Sleeping better
☐ Reducing bathroom urgency
☐ Getting more exercise
☐ Attending social events
☐ Managing work or school responsibilities
☐ Strengthening emotional well-being
☐ Building confidence with food choices
☐ Improving medication routine
☐ Feeling more in control day to day
☐ Others:_______________

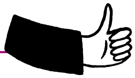
Define short- & long-term goals



Step 2 Try the SMARTER method

Now that you've picked a priority, use the SMARTER method to turn it into a **clear, actionable goal.**

- **S Specific:** What exactly do you want to accomplish?
  I want to ____
- **M Measurable:** How will you know you are making progress?
  I will track it by __________________________________
- **A Attainable:** Is this goal realistic for you right now?
  I can take small steps like _________________________
- **R Relevant:** Why is this goal important to you?
  This matters because _______________________________
- **T Time-bound:** When do you want to reach this goal?
  I will work on it for _______________ weeks/months and check in on _____________________________________
- **E Evaluate:** How will you reflect on your progress?
  I'll check in weekly and adjust if needed by __________ ____
- **R Reward:** How will you recognize your effort?
  I'll celebrate by __________________________________



Step 3: Share your goals with the IBD team

Your care team can help refine your goal, suggest strategies, and support you along the way. Bringing your goal to your next appointment is a great first step. (*Refer to:* **Navigate healthcare resources and Get active in decision making.**)

Conclusion: Take charge of your journey

One step at a time

Living with IBD is a journey, but you don't have to walk it alone. The ENGAGE-IBD guide is here to support you in taking active steps toward better health and well-being.

It's not about doing everything at once. Choose one area that matters most today—and start there. Small steps can lead to meaningful progress.

Each part of this cycle—from building emotional resilience to making shared decisions—can help you feel more in control, confident, and supported.

Revisit this guide when you need a boost, reflection, or fresh ideas for navigating your condition with clarity and purpose.

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Your guide to engage in living well with
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