

Talking to your family and friends about living with Inflammatory Bowel Disease (IBD)

You've only just learned about Inflammatory Bowel Disease (IBD), and now you **need to talk to your family and friends** about it. Discussing your condition with those closest to you can help them to better understand IBD and ensure they're equipped to support you when you need it. But asking for help can be hard and you might find speaking about intimate details of your personal health challenging. That's why we've created this **conversation guide to help you to better understand this complex condition and explain to others** how it is going to impact your life.

Remember:

- Relying on a good support network is important to make sure you receive the help you need. While speaking openly about your health may be challenging, try not to feel embarrassed. Having these conversations can help others to understand your triggers and what your specific needs are.
- There is a lot of misinformation online so it is helpful to explain the facts and dispel any misconceptions they may already have e.g. IBD is caused by too much stress or by eating junk food.
- It can be frustrating not to be able to do some of the things others take for granted. If you've only just been diagnosed, you may feel uncertain, anxious, depressed or even angry. Feelings like these are only human, and everyone reacts in their own way. Make sure you reach out for support. You may find keeping a journal helps you to focus on what you want to talk about.
- Patient groups are also a great way to get support as sharing your emotions with others in the same situation can really change your outlook!

Where do I start?

- Think about the people in your life who you want to discuss your condition with. As you will be sharing very personal details, it's important to identify the close friends and family members you feel comfortable opening up to and who can be there to support you.
- Planning your conversation in advance can help you to make the most of the discussion. You may find writing down a list of key points you want to cover beforehand helps you to work out what you want to say.
- Choose a time and a place where you will feel the most comfortable – this could be face-to-face or over the phone. There is no right or wrong option, simply do whatever feels right for you.
- Take all the time you need. You don't necessarily need to cover everything you want to say at once – you may find it easier to have several conversations spread out over time.

What shall I say?

We've prepared a list of some of the top 7 topics that might come up when explaining IBD to your friends and family. These cover some of the most common questions people have about the disease.

1. The difference between IBD and Irritable bowel syndrome (IBS)

- IBS is a common condition that causes bloating, stomach pain, constipation, and diarrhoea.¹
- IBD is more severe and can cause severe inflammation, ulcers, or other structural damage.¹
- The term IBD covers two chronic (long-term or life-long) gastrointestinal conditions.²
 - **Ulcerative Colitis (UC)** which affects the colon (large intestine)^{1,2}
 - **Crohn's Disease (CD)** which affects any part of the digestive system, from the mouth to the anus.^{2,3}

2. The causes of IBD

Nobody really knows the exact cause of the condition and it involves a combination of factors including the genes you are born with, an abnormal reaction of the immune system to certain bacteria in your gut, and an unknown trigger which may be associated with diet or stress.³

3. Who is affected by IBD

- IBD affects around 4.3 million people in Europe every year and that number is growing.⁴
- It is usually diagnosed in young adults between the age of 15 and 30, however it can be found in people of all ages – including children. It can also be diagnosed later in life in people between the age of 60 and 70.^{3,5}
- The chances of developing IBD is the same for women and men.⁶

4. The common symptoms of IBD

- Fatigue, fever, weight loss, abdominal pain, diarrhoea, constipation, blood and/or mucus and/or pus in the stool are common to both UC and CD.⁷⁻⁹
- Some people may also develop anaemia or problems with their joints, skin, and eyes.⁸
- IBD can be more severe in children, as it can affect growth rates or delay puberty.¹⁰⁻¹²

5. How IBD impacts your diet

- Symptoms can be triggered by any number of things including certain foods¹³ or stressful situations and they often come and go without warning.^{10-12,14}
- When there is more inflammation you experience more symptoms, which is called a 'flare-up'. The time between flare-ups, when there are no symptoms, is called 'remission'.¹⁰⁻¹³

- It's generally best to avoid gassy foods or large meals and to only eat a moderate amount of fibre.¹³
- When travelling, you can only use bottled water for drinking, brushing your teeth and washing food.¹⁵ It's also best to avoid ice cubes, street food and raw or undercooked foods.¹⁵

6. Discussing IBD with your partner

- If you're in an intimate relationship be honest with your partner about your emotions and physical challenges.
- If you and your partner want to start a family, rest assured that most people with IBD do have a healthy pregnancy and baby and be sure to speak to your doctor about a treatment plan.¹⁶

7. How friends, family and carers can support you

- Learning to live with IBD involves coping with a lot of unknowns so it can be helpful to take each day as it comes and set small, achievable goals. You can share these goals with your friends and family and ask them to help support you in reaching them.
- Your carer, friends or family could help think of ways to make each day a little bit easier, so you can reserve your energy for activities you enjoy. This could include preparing a "just in case" kit together for when symptoms suddenly arise (find out more on the 'Managing Symptoms' page of JanssenWithMe).¹⁷
- It's common to experience extreme fatigue with IBD. If you let your family and friends know that sometimes you may need to change plans suddenly – such as leave a gathering early or decline invitations altogether – they can be more accommodating and you can make sure you take the time out you need to rest.¹⁸
- The people around you can help plan mealtimes so you can avoid the triggers that cause flare-ups. You could even ask for their help cooking multiple portions and freezing meals so they're always on hand.¹⁸
- Physical activity is important for overall wellbeing and can even help you manage IBD – but you have to find exercise that works for you. You could try out less intensive activities like yoga or swimming at first and perhaps try working out with friends or family to stay motivated.^{18,19}

Finally, don't forget to remind yourself and your friends and family how important it is to keep a positive mindset, especially on a bad day. Many people living with IBD lead happy and productive lives.

Watch the '**My IBD Journey: Life after diagnosis**' for practical tips on positive steps to take following an IBD diagnosis and how to live well with it!

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