

## Executive summary

# The power of community in inflammatory bowel disease: Coming together to reduce physical and psychosocial impacts

Inflammatory bowel disease (IBD), which includes Crohn's disease and ulcerative colitis, affects nearly three million people in the United States (US).<sup>1</sup> Many people with IBD look healthy on the outside, but they may deal with several "invisible" symptoms like constant stomach pain, frequent and sudden need for the bathroom, fatigue, and mental health challenges.

In 2014, recognizing these challenges, Johnson & Johnson (J&J) founded IBD Social Circle (IBDSC), a community of patients, care partners, and healthcare providers (HCPs) dedicated to turning lived experiences into resources so no one feels alone on their IBD journey. To highlight how physical and mental factors of IBD impact patient care and understand the role community plays to support people living with it, J&J commissioned a white paper, developed with IBDSC patient advocates, HCPs, and data from a recent survey of 500+ US adults with IBD.\*

## Life with IBD: The hidden challenges

Living with IBD can be complex and impact all aspects of someone's life. Here's how<sup>2</sup>:

**80%**

of people with IBD say it is **harder to socially engage** with others due to their IBD and

**78%**

feel **isolated**

**85%**

of people with IBD feel **misunderstood**



On average within a year, a person with IBD **misses**

**14 days**

**of work and four major life events**, like birthdays and weddings

**More than half**

of people with IBD say it negatively affects their **mental well-being** (52%)



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Patients living with IBD are more than a GI tract. They are a whole person with a disease that negatively impacts many aspects of their life, and many patients feel that others (including friends and family) do not fully understand how IBD is affecting their psychosocial health, relationships, work, finances, and simple daily activities.”



**Aline Charabaty, MD, AGAF, FACG**  
Gastroenterologist,  
Johns Hopkins School of Medicine

## The power of community for those living with IBD

Research has shown that a strong community and support system are critical for people with IBD. People with IBD who have actively engaged with the IBD community report doing so has changed the trajectory of their IBD journey for the better, including<sup>2</sup>:

**9 in 10**

found it helped them **better manage** their IBD (88%)

**33%**

felt **less isolated**

**32%**

learned to **better advocate** for themselves

**39%**

learned to **better communicate** with healthcare providers

**44%**

felt **improvements in** their **mental health and well-being**

## Use this white paper to drive change

The challenges faced by people with IBD are significant, but there are many ways to help make a difference:

### As someone living with IBD

**Connect with the IBD community:** Learn about others' experiences with IBD and be open to conversations with your care team and loved ones about ways they can support you.

### As someone who has a loved one living with IBD

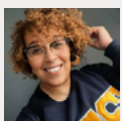
**Practice empathy and understanding:** Remember that IBD is an "invisible" illness. Recognize that plans may change due to their health and ask how you can best support them.

### As someone who wants to do more

**Help reduce stigma:** Encourage others to learn more about IBD, including addressing misconceptions associated with the disease.

**“**

I don't know if I would have made it this far without the IBD community. I lost my home, career, husband, and insurance due to not understanding how the disease works. Having resources, being able to talk about feelings, learning how to find a physician—for me, community has been indispensable.”



**Brooke Abbott Abron**  
IBDSC patient advocate

Together, we can create a more understanding and supportive world for everyone living with IBD.

To read the full white paper and learn more about the IBD community, visit [IBDSocialCircle.com](https://www.ibdsocialcircle.com) or scan the QR code.



Data rates may apply.

### References:

<sup>1</sup> Crohn's & Colitis Foundation. Overview of Crohn's disease. Accessed July 2025. Available at: <https://www.crohnscolitisfoundation.org/what-is-crohns-disease/overview>

<sup>2</sup> IBD Social Circle. The power of community in inflammatory bowel disease: Coming together to reduce physical and psychosocial impacts. Accessed September 2025. Available at: <http://www.ibdsocialcircle.com/community-ibd-whitepaper>