

New insights into the importance of treating the “whole self”

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

The burden of managing inflammatory bowel disease (IBD) reaches far beyond the gut, impacting patients' whole lives, even for those in a state of remission. Promoting community support and providing resources, such as mental health and nutrition counseling, can help shift IBD care from finding the right treatment to treating the “whole self” and help improve quality of life for these patients.

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 psychosocial factors impact patient care and understand how community can support IBD management, J&J commissioned a white paper, developed with IBDSC patient advocates, HCPs, and data from a recent survey of 500+ US adults with IBD.*

The unseen burden

IBD is a complex condition with challenging physical symptoms, but those living with IBD experience an equally significant psychosocial burden. Here's how¹:

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**, despite feeling supported by their loved ones and their HCPs

More than half

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

95%

said they look for **IBD information and resources beyond what their physician provides** or discusses with them



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Community support is so critical, because I can sit here all day and tell my patients what living with IBD is going to be like. But I haven't been there myself. Hearing it from people who have gone through this journey is really validating and encouraging for patients and care partners, spouses, and other family members.”



Amy Stewart, FNP-C
Nurse Practitioner, Capital Digestive Care

The power of community for those living with IBD

HCPs can help their patients build a strong support system. 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, including¹:

9 in 10

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



39%

learned to **improve their ability to communicate** with their HCPs



39%

became **more informed** about IBD treatment options



44%

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

“

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

Actionable strategies that can make a difference

Addressing the psychosocial needs and connecting patients with community resources is essential to help improve patient outcomes, including:

Ask about mental health and social well-being

Create a safe space for open dialogue by asking about anxiety, depression, and quality of life, even for patients in remission.

Collaborate with a multidisciplinary team

Partner with other specialists to address the full spectrum of patient needs while involving patients in treatment choices.

Connect patients with their peers

Encourage patients to find support through community.

Provide culturally conscious care

Understand and respect diverse cultural backgrounds, dietary preferences, and potential medical mistrust, especially in minority communities.

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Our role as healthcare providers allows us with the unique opportunity to connect with IBD patients by understanding their struggles and offering support. This connection fosters a true partnership, empowering patients to advocate for their needs and approach their future with greater hope.”



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

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 or scan the QR code.



Data rates may apply.

References:

¹ 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>