



A PROFESSIONAL'S GUIDE TO SUPPORTING, ENGAGING, AND PROTECTING IBD PATIENTS AND CAREGIVERS

ABOUT THIS GUIDE

In September of 2019, the National Alliance for Caregiving, the Crohn's & Colitis Foundation, and ImproveCareNow released findings from the first-ever *National Study on Caregivers of People with Crohn's Disease or Ulcerative Colitis*. The study findings highlighted unmet needs of family caregivers who are caring for patients living with inflammatory bowel disease (IBD).

Our 2019 report found four major need gaps facing IBD caregivers that we believe frontline clinicians can help to address, including:

1. The need for ease of access to evidence-based information and resources;
2. The need for clinicians to facilitate shared decision-making with the caregiver, patient, and the rest of the care team;
3. The need for medical professionals, such as a treating physician, surgeon, or nurse to consider how to better provide training to IBD caregivers, particularly for medically complex tasks; and
4. The need to support and protect caregivers' well-being.

This informational guide is intended to improve the care of people living with IBD and the friends and family who support them. In the following pages, you will find tips on how to partner with IBD caregivers to ensure that they are engaged and empowered to participate in shared decision-making processes with the care team.

For the latest research on the state of IBD caregivers, visit [caregiving.org/IBD](https://www.caregiving.org/IBD).



National Alliance for Caregiving

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STRATEGIES

With information gathered from a series of interviews with IBD providers, patients, and caregivers, we've identified 4 strategies that providers and health professionals can implement to better support and engage IBD patients and caregivers.

- 1 Equip patients and caregivers with reliable information and tools to manage IBD
- 2 Engage patients and caregivers in shared and supported decision-making
- 3 Ensure caregivers and patients are equipped to perform medical and nursing tasks
- 4 Protect the mental health and wellbeing of people living with IBD and their families

STRATEGY 1

EQUIP PATIENTS AND CAREGIVERS WITH RELIABLE INFORMATION AND TOOLS TO MANAGE IBD

Study finding

Two-thirds of caregivers report needing access to education support services. Moreover, nine out of 10 IBD caregivers report doctors being their first go-to source for information.

What it means

Open communication between physicians and the family are key to improving the IBD caregiver's understanding of how to support their care recipient.

What you can do

- Provide the caregiver and patient with resources to allow them to legitimize their concerns and properly voice them to their clinician.
- Streamline communication within the care team by using patient portals to share resources, answer follow-up questions, and create opportunities for conversation outside of the doctor's office. Ask, or have a nurse ask the caregiver: "Are you having any problems? Are there aspects you don't understand?" Building trust and allowing open dialogues empowers patients and caregivers to be actively involved in the care process.
- When referring patients to specialists, such as nutritionists or gastroenterologists, engage those specialists in open-communication with the entire care team to ease the shared decision-making process.
- Have open discussions with patients about what supplements they are taking and alternative treatments they may be pursuing.
- Explain medical procedures, decisions, and terms clearly without oversimplifying. Make sure the patient and caregiver understand by asking follow-up questions.

"The disease is stressful, but feeling like a bother when talking to a doctor is even more stressful. Open lines of communication are a struggle."



"There needs to be a better understanding from doctors and surgeons about the need for nutritional counseling for patients with IBD... food is a huge obstacle for patients with these conditions."



“My biggest hurdle was getting people to understand the seriousness of my daughter’s illness. Many people, including extended family, don’t even know what IBD is or how severe it can be. Those who are familiar with it will cite people who have a mild form or have been able to control it successfully with medication... My daughter had severe Crohn’s. Thirteen medications failed her, including the biologics that worked before her body developed antibodies.”

STRATEGY 2

ENGAGE PATIENTS AND CAREGIVERS IN SHARED AND SUPPORTED DECISION-MAKING

Study finding

While findings indicate that the caregiver is actively involved in advocating for their care recipient’s health, many report having trouble communicating with their clinicians and understanding their role in shared decision-making.

What it means

There is an increased need for better engaging the caregiver, care recipient, and members of the healthcare team in shared decision-making.

What you can do

- Decision-making is not a purely objective process. There are subjective perspectives that go into clinicians’ choices for treatment, and both the patient and caregiver should be empowered to share their perspectives. The caregiver notices small things about the patient’s condition that the patient might forget to mention, such as his mood, what he ate, etc. 87% of IBD caregivers live with their care recipient: they are living with the disease every day, just as the patient is. Ask them for their perspective.
- If patients and caregivers are comfortable with the treatment plan, there is a higher chance they will cooperate with it. Make the patient’s and caregiver’s role clear in the shared decision-making process to allow them to comfortably voice their perspective on a treatment plan. Working together to weigh out the options, and finding one they are most comfortable with will increase the chance for treatment success.
- Children with IBD tend to be left out of the decision-making process, and are thus not empowered in their own care. Involve both the caregiver and patient in decision-making regardless of their respective ages. Children and adolescents with IBD need to be prepared for the day they will attend appointments on their own and should be empowered early on in their care journey.

“Finally, when he was 17 or 18 years old, I had an epiphany and realized I needed to back off, and that he was an adult and needed to take more responsibility. When I told him this, he said it was what he had been waiting to hear. The weight off my shoulders was immense.”

– Parent family caregiver

STRATEGY 3

ENSURE CAREGIVERS AND PATIENTS ARE EQUIPPED TO PERFORM MEDICAL AND NURSING TASKS

Study finding

Of the caregivers who reported conducting medical/nursing tasks, only about one-third reported having received prior preparation or training.

What it means

Medical professionals should consider how to provide training to IBD caregivers, particularly for medically complex tasks, such as operating hospital equipment or ostomy care, which is described as the most difficult medical task performed by caregivers.

What you can do

- After instruction or training on a medical task is given, caregivers and patients may nod their head indicating they've understood the task, but clinicians should always make sure the caregiver understands what they're supposed to do by asking follow-up questions or providing them with additional training resources.
- Have a nurse follow-up with the patient or caregiver, either through a phone call or patient portals, to make sure they are comfortable with the medical task at home.

"When I was a caregiver, there really wasn't much support available. Looking back, I wish I had asked for more help and sought out resources. This was a very difficult time for our family emotionally and financially. We are better suited now to advocate for him now that we've gone through the difficult times. And to provide support for others going through the same diagnosis."



STRATEGY 4

PROTECT THE MENTAL HEALTH AND WELLBEING OF PEOPLE LIVING WITH IBD AND THEIR FAMILIES

Study finding

More than 1 in 5 caregivers reported poor or fair physical health, and twice as many said their emotional health was fair or poor when last providing care. Nearly half (49%) of IBD caregivers reported feeling very or extremely overwhelmed. One third of caregivers reported experiencing guilt over not doing a better job at caregiving.

What it means

Considering caregivers' dependence on their care recipient's clinician for information, resources, and support. Providers play an important in protecting and supporting caregivers', and patients', emotional well-being.

What you can do

- Address the emotional impacts of the disease. Ask patients and caregivers about their mental health. If needed, refer them to mental health professionals and equip them with resources to support their mental health.
- Share caregiving-specific resources with the caregiver, such as:
 - Resources to help support and motivate IBD care recipients;
 - Resources for intimate couples in which one partner has IBD;
 - Information on caregiver-accessible care teams in IBD centers;
 - Support groups for their specific care situation (i.e. parent support groups or adolescent patient support groups).

"I wish more people realized the effects of IBD on the whole family unit, and the caregiver burnout... The long-term management of a child's health is exhausting."

"As a caregiver, I've often felt like I'm not supposed to talk about my own struggles... I think the impact of IBD on a family reaches far past the patient."

"The isolation compounds the depression of living with this disease."

– Caregiver



SUPPORTING FAMILY CAREGIVERS

In this guide, we've provided four strategies for integrating a friend or family member into the plan of care for someone living with IBD. Many health and long-term care systems have started to pave pathways to encourage formal care providers to work more closely with family caregivers.

For Medicare Advantage and Traditional Medicare Patients

Medicare providers may be eligible for family support services to the family caregiver.

- **Medicare Advantage** plans may have a respite care benefit available to caregivers, in order to give them a break from supporting activities of daily living. Under the Special Supplemental Benefits for the Chronically Ill program, plan benefits may also include access to companion care, marital counseling, family counseling, caregivers of children, or programs that can help address isolation and improve emotional and/or cognitive function.
- Under **Traditional Medicare**, some CPT (or "billing") codes may allow a provider reimbursement for services provided to a family caregiver, including:
 - Transitional Care Evaluation and Management Services (99495)
 - Chronic Care Management Services (99490, 99491, 99487, 99489)
 - Training and/or Education of Patient or Family Member (G0495-496, 99341-350, 99324-337, 99201-215)
 - Remote Patient Monitoring and Review of Digitally Stored Data (99091)
 - Remote Chronic Care Physiologic Monitoring Treatment Management Services (99457)
 - Patient or Caregiver Training for the Initiation of Home International Normalized Ratio Monitoring (93792)
 - Comprehensive Clinical Visit that Results in a Written Care Plan (99483)
 - Administration of Caregiver-Focused Health Risk Assessment Instrument, For the Benefit of the Patient, with Scoring and Documentation, Per Standardized Instrument (96161; see also 99201-215, 99381-395)

- **Conditions of Participation under Medicare Part B** programs may require long-term and post-acute care providers to offer education for a caregiver and engage in shared-decision making, particularly as it relates to discharge to a long-term or post-acute setting, the end-stage renal disease benefit, transition to home health, transition to hospice, or the use of durable medical equipment.

State Specific Supports

- Under the **Medicaid Program**, caregivers may be eligible to participate in the self-directed care program and may potentially receive financial support for care provided through the Home and Community Based Waiver Programs under section 1915.
- A majority of states have passed the **Care, Advise, Record, and Enable (or "C.A.R.E.") Act**, which requires education of the family caregiver on discharge from a hospital setting to the home, and inclusion of the caregiver in the medical record.

Home and Community Based Supports

- Caregivers of adults with disabilities, older adults, and grandparents caring for children can receive caregiver supports through the **National Family Caregiver Support Program**, which can be accessed through eldercare.acl.gov or by calling 1-800-677-1116.
- **Caregivers of military Veterans** may be eligible for various programs, including the Program of General Caregiver Support and the Program of Comprehensive Assistance for Family Caregivers, which can be accessed through caregiver.va.gov or by calling 1-855-260-3274.
- Caregivers who need respite may find services through the Lifespan Respite Program; local supports can be found via **ARCH National Respite Network's Respite Locator** at archrespite.org/respitelocator.



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ABOUT THE STUDY

The 2019 study defined an IBD caregiver as an individual who provides unpaid or volunteer care to a friend or relative living with IBD. The study focused on those caregivers who are 18 years or older caring for either an adult or child care recipient diagnosed with IBD. The September 2019 report can be accessed by going to www.caregiving.org/ibd. This guidebook is based on this 2019 report, as well as a series of interviews with physicians specializing in IBD and IBD-patient advocates. The guidebook is meant to ensure that the findings from our 2019 national study on IBD caregivers are communicated in a way that clinicians that see and work with IBD patients and caregivers on diagnosis and treatments on the frontline can use the information in their practice to better support them.

ABOUT THE NATIONAL ALLIANCE FOR CAREGIVING

Established in 1996, the National Alliance for Caregiving is a non-profit coalition of national organizations focusing on advancing family caregiving through research, innovation, and advocacy. The Alliance conducts research, does policy analysis, develops national best-practice programs, and works to increase public awareness of family caregiving issues. Recognizing that family caregivers provide important societal and financial contributions toward maintaining the well-being of those they care for, the Alliance supports a network of more than 80 state and local caregiving coalitions and serves as Secretariat for the International Alliance of Carer Organizations (IACO). Learn more at www.caregiving.org.



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