



Inflammatory  
Bowel Disease

# KNOW YOUR RIGHTS

*A resource for patients with  
Inflammatory Bowel Disease (IBD).*

 **AIMED ALLIANCE**

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## INFLAMMATORY BOWEL DISEASE DIAGNOSIS & TREATMENT

Inflammatory Bowel Disease (“IBD”) is an autoimmune disorder that causes chronic inflammation in the digestive tract.<sup>1</sup> IBD encompasses both Crohn’s Disease and ulcerative colitis.<sup>2</sup> While Crohn’s Disease and ulcerative colitis share similar symptoms, they affect different areas of the gastrointestinal (“GI”) tract. Generally, IBD causes symptoms such as abdominal pain, diarrhea, bloody stool, constipation, and an urgent need to empty the bowel.<sup>3</sup>

IBD is very prevalent in the United States, with the Centers for Disease Control and Prevention estimating that 3.1 million Americans have been diagnosed with IBD.<sup>4</sup> Additionally, certain forms of IBD can be more prevalent in specific patient populations. For example, studies have found that Crohn’s Disease is more prominent in women than men.<sup>5</sup>

### Crohn’s Disease

Crohn’s Disease can cause individuals to experience inflammation within their GI tract. Most often this inflammation is found at the end of the small intestine, called the ileum,

and the beginning of the large intestine, called the colon.<sup>6</sup> Symptoms of Crohn’s Disease vary from person to person, but generally include cramping, pain in the middle or lower abdomen, diarrhea, loss of appetite, weight loss,<sup>7</sup> rectal bleeding, anal fistulas and ulcers, skin lesions, and/or joint pain.<sup>8</sup>

### Ulcerative Colitis

Ulcerative colitis is characterized by chronic inflammation in the colon. This inflammation causes small sores known as ulcers to form on the colon.<sup>9</sup> Unlike Crohn’s Disease, which can affect the entire thickness of the bowel wall, ulcerative colitis only affects the inner most lining of the colon.<sup>10</sup>

The specific cause of ulcerative colitis is unknown. Several factors including abnormal immune response, genetics, microbiome, and environmental factors all contribute to the development of the disease.<sup>11</sup> Further research has also shown that the disease could be triggered by the immune response to a viral or bacterial infection in the colon.<sup>12</sup> Symptoms of ulcerative colitis can include diarrhea,

abdominal pain and cramping, rectal pain and/or bleeding, weight loss, fatigue, fever, and inability to relieve the bowel despite urgency.<sup>13</sup>

## Diagnosis

Health care providers can use a variety of methods to diagnose and monitor IBD. During a physical exam, health care providers may first assess an individual's abdomen to check for pain or tenderness. Health care providers may also use tests to confirm an IBD diagnosis. Most often, health care providers use endoscopic procedures to diagnose IBD. While there is no blood test that can confirm an IBD diagnosis, health care providers can use blood tests to rule out other conditions with symptoms similar to IBD.

Endoscopic procedures are an important diagnostic tool for IBD as they provide health care providers views of the GI tract.<sup>14</sup> There are multiple types of endoscopic exams that a provider may select depending on the individuals' symptoms, medical history, physical exam, and results of blood and stool tests.<sup>15</sup> A colonoscopy is the most commonly used endoscopic method. Health care providers may also use imaging tests in combination with endoscopic tests, such as MRIs, x-rays, and computerized tomography (CT) scans to help identify whether an individual has IBD.

## Treatments

While there is no known cure for IBD, there are many treatments available to help alleviate symptoms of IBD. Promptly finding an

effective treatment is important for patients, as untreated IBD symptoms can worsen over time and can lead to an increased risk of colon cancer.<sup>16</sup> Treatments for IBD include medications such as corticosteroids, 5-aminosalicylic acid medications, immunomodulatory medications, biologic therapies, anti-tnf agents, and anti-integrin therapy. For some patients with IBD, health care providers may also recommend surgical interventions and removal of part of the GI tract to address IBD symptoms. Nearly 20 percent of patients with ulcerative colitis and up to 80 percent of patients with Chron's Disease will undergo surgery at some point.<sup>17</sup>

People with ulcerative colitis or Chron's Disease can also experience occasional flares in which their symptoms return or worsen.<sup>18</sup> Many factors can contribute to a flare such as skipping or taking the wrong dose of medication, taking nonsteroidal anti-inflammatory drugs (NSAIDs), taking antibiotics, smoking, experiencing stress, and eating foods that irritate the GI tract.<sup>19</sup>

## Health Insurance Coverage of IBD Care

Health insurance companies often take a number of steps to reduce their costs related to IBD diagnosis and treatment. For example, health plans may limit coverage of certain treatments prescribed by your doctor, or the plan may require you to take a series of steps before your treatment is approved. Fortunately, there are state and federal laws in place that may protect you from these practices.

To find out whether your health insurer has delayed or denied your prescribed IBD treatments, ask yourself the following questions:



## **STEP THERAPY**

***Did my insurer make me try a different treatment before covering the IBD medication or therapy that my doctor prescribed?***

This practice is called “step therapy” or “fail first” because it requires patients to try other treatments first and demonstrate that they do not work or are intolerable, often causing discomfort and burdensome experiences while the patient waits. An insurer may require patients to try and fail a different medication or therapy before covering the one prescribed by their care team.<sup>20</sup> Step therapy is a common practice utilized by almost 60 percent of insurers.<sup>21</sup> Step therapy is also common for patients with IBD, with one survey finding that 40 percent of patients with IBD were subject to a step therapy policy.<sup>22</sup> Additionally of those 40 percent, 58 percent were required to fail on more than one treatment before being able to access their originally prescribed treatment, and 60 percent were unable to have a doctor step in to override the step therapy process on their behalf.<sup>23</sup> Step therapy can also interfere with access to care, as 32 percent of surveyed patients with IBD reported delays for over seven months in accessing their treatment. Fortunately, there are steps patients can take to better navigate the step therapy process and ensure they can access their treatments. Step therapy policies may also violate federal or state laws if an insurer treats patients with similar diagnoses differently because of their health condition.<sup>24</sup> Additionally, patients may be entitled to an exception from the step therapy process.



## **NON-MEDICAL SWITCHING**

***Is my insurer forcing me to take a different medication, even though my current IBD treatment is working, by refusing to cover it any longer or increasing my copay?***

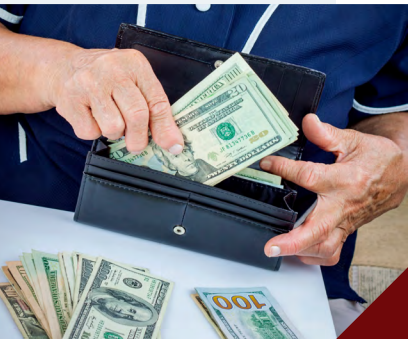
This practice is referred to as “non-medical switching.” It occurs when an insurer (not a health care professional or pharmacist) forces a patient to switch from their current medication to a different (but not a generic equivalent) medication by either refusing to cover the drug any longer or increasing the out-of-pocket cost of the drug.<sup>25</sup> In addition to having harmful repercussions, non-medical switching may also violate certain states’ consumer protection laws.<sup>26</sup>



## PRIOR AUTHORIZATION

*Do I need to get my insurer's approval before I can begin or continue my prescribed IBD treatment or therapy?*

This practice is called "prior authorization." It happens when an insurer requires the patient or their doctor to get your insurer's approval before the treatment is covered. Approval is based on the insurer's standards, which may be inconsistent with medical standards of care and harmful to patients. For example, one survey found that 92 percent of physicians reported prior authorization policies had a negative impact on clinical outcomes.<sup>27</sup> For those living with IBD, the results can be devastating and costly. One study found that prior authorization resulted in patients with IBD experiencing delays in accessing treatment and increased IBD-related healthcare utilization costs.<sup>28</sup> Further, one study found that a prior authorization process increased the patients delay in access to treatment by ten days.<sup>29</sup> These policies can also violate state and federal laws if applied in a certain manner.



## ADVERSE TIERING

*Do I have to pay a high copay for certain medications that treat my condition?*

This practice is called "adverse tiering." It can be used by insurers to shift much of the cost for newer or innovative therapies to patients by placing expensive drugs on what are called "specialty tiers." Certain tiering policies may also violate certain federal and state laws if used in a discriminatory way.<sup>30</sup>



## COPAYMENT ACCUMULATORS

*If I receive coupons or discounts to help pay for my medication copays, does my insurer prohibit those coupons or discounts from counting toward my annual deductible?*

This policy is known as a "copayment accumulator." Copayment accumulators force patients to pay more out of pocket when copayment assistance runs out and the insurance deductible has not been met. These policies are frequently buried in the fine print of insurance contracts and may violate state consumer protection laws.<sup>31</sup>

My insurer refuses to cover an IBD treatment or therapy that my health care professional prescribed to me. **What can I do?**

If your insurer refuses to cover your treatment, here are three steps you can take to try and change your insurer's decision:

- Appeal the decision;
- Request an external review; or
- File a consumer complaint.



## How do I appeal the decision?

If your insurer denies your claim, you have the legal right to an internal appeal.<sup>32</sup> This means you can ask your insurer to conduct a full and fair review of its decision. To appeal the denial, you should do the following:



**Review the determination letter.** Your insurer should have sent you a determination letter to tell you that it would not cover your claim. Review this document so you can understand why your insurer denied your claim and how you can appeal the denial.



**Collect information.** Collect the determination letter and all other documents the insurance company sent you. This includes your insurance policy and your insurer's medical necessity criteria. "Medical necessity criteria" refers to your insurer's policy for determining whether a treatment or service is necessary for your condition.<sup>33</sup>



**Request documents.** If you did not receive the determination letter or do not have your policy information, the medical necessity criteria, or the instructions and forms for filing an appeal, call the insurer's customer service representative and ask for these documents. The company website will list the toll-free telephone number to call.



### **Call your health care professional's office.**

The health care professional's office or clinic has people on staff to help with the appeal process. They will tell you how to fill out the forms to request an appeal, write an appeal letter on your behalf, or handle the appeal request for you.



**Submit the appeal request.** It is important for you or your health care professional's office to submit the appeal request as soon as possible along with the letter from the health care professional and all additional information the insurer requested.



### **Once you file an appeal request, expect to wait up to 30 days to hear back from the insurance company regarding a treatment you hope to receive.**

It can take up to 60 days for a response if you received the treatment and are waiting for reimbursement.



**Follow up.** Follow up with your insurer regularly until you hear back. Be sure to keep a record of the name of any representative you speak with about the appeal, the date and time you spoke with that person, a confirmation number for the call, and a summary of your discussion.



## What if my insurer denies my appeal?

Under law, you are entitled to take your appeal to an independent third party for an “external review,” which means the insurance company no longer gets the final say over whether to approve a treatment or pay a claim. The situation applies if the insurer denies your appeal or if your medical situation is urgent and waiting would jeopardize your life or ability to function.

## How do I request an external review?

To trigger an external review, file a written request with the independent organization within 60 days of the date your insurer sent you a final decision. The process should take no more than 60 days. However, in urgent situations requiring an expedited review, the process should take no longer than four business days. To find out whom to contact in your state to request an external review, please go to [www.CoverageRights.org](http://www.CoverageRights.org).

## How do I file a complaint?

If your insurer denies your coverage after the external review process, you can file a complaint with the insurance commissioner or attorney general in your state. To determine whom to contact and how to submit the complaint, please go to [CoverageRights.org](http://CoverageRights.org).

Your complaint should include the following information:

- The name, address, email address, and telephone number of the person filing the complaint (“Complainant”);
- The name of the insured individual, if different from the Complainant;
- The names of any other parties involved in the claim (for example, the plan administrator or pharmacy benefit manager);
- The name of the insurance company and the type of insurance;

- The state where the insurance plan was purchased;
- Claim information, including the policy number, certificate number, claim number, dates of denial, and amount in dispute;
- The reason for and details of the complaint; and
- What you consider to be a fair resolution.

You should also submit the following supporting documents with your complaint:

- A copy of your insurance card;
- Copies of coverage denials or adverse benefit determinations from your insurer;
- Copies of any determinations made by internal and external reviewers;
- Any materials submitted with prior appeals and complaints;
- Supporting documentation from your health care professional;
- A copy of your insurance policy; and
- All responses from your insurer.

## What happens after the insurance commissioner or attorney general receives my complaint?

The insurance commissioner or attorney general will assign someone to research, investigate, and resolve your complaint. That person will examine your account, records, documents, and transactions. He or she may question witnesses, request additional documents from other parties, and hold a hearing. If the insurance commissioner or attorney general determines that the insurer violated laws or regulations, he or she may order the insurer to give you the requested coverage or compensate you.

## Whom should I call if I have any questions about filing a complaint?

To determine whom to call in your state, please go to [www.CoverageRights.org](http://www.CoverageRights.org).



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1455 Pennsylvania Avenue NW, Suite 400 • Washington, DC 20004  
202-349-4089 • [AimedAlliance.org](http://AimedAlliance.org)