

# PATIENT PERSPECTIVE

Current Developments in the Management of Patients With Irritable Bowel Syndrome With Constipation

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## Patient-Provider Conversation About IBS-C Treatment With Tenapanor



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**CH** When were you first diagnosed?

**Patient** I was first diagnosed approximately 10 years ago. I suffered from very bad constipation with bloating and pain. It took me a while to find the right doctor, but when I did, she was the one who gave me an official diagnosis of irritable bowel syndrome with constipation (IBS-C).

**CH** In my experience, patients with IBS-C often live with their symptoms for a long time before they first present for evaluation, and their symptoms are extremely burdensome to daily living and quality of life. This is one of the most frustrating conditions for both patient and provider.

When did you start to seek out your own information about treatment options?

**Patient** I knew that I had a problem, but it took a long time to get a diagnosis. I was always told it was just constipation and pain and that I should just take over-the-counter drugs. However, I always knew that there was something more. I started to see commercials for medications for these symptoms, and I realized I might have that condition.

**CH** What are the symptoms you have predominantly experienced?

**Patient** Mostly very bad constipation, horrible pain, and very bad bloating.

**CH** Abdominal pain and hard stools are considered the hallmark symptoms of IBS-C and may be accompanied by other abdominal symptoms such as discomfort and bloating as well as bowel-related symptoms such as

infrequent stools, straining, and sensations of incomplete evacuation. An analysis of the IBS in America 2024 survey found that the most frequent symptoms after constipation were bloating, abdominal cramps and pain, abdominal fullness, and excessive gas/flatulence. As a clinician, I feel like bloating is one of the most burdensome and difficult-to-treat symptoms that patients with IBS-C experience, and bloating and pain can be some of the biggest complaints.

How has IBS-C impacted your relationships and activities?

**Patient** It has affected me physically, mentally, and socially. I have had to miss a lot of activities for my children and family because I was not feeling well. Sometimes I could not go to work because I was in so much pain and was on the couch with a heating pad. This happened often with flares and was a vicious circle. Then I would get anxiety because I knew what was coming and would get depressed.

**CH** In the IBS in America 2024 survey, the vast majority of patients reported at least some negative or a significant negative impact of IBS-C to their overall quality of life. Patients with IBS-C are living with chronic symptoms that are not visible to others, so there can be a lack of understanding and patients can often feel alone and isolated. Soon if patients are not able to go out, other people just stop engaging with them.

**Patient** That is exactly what happens. You feel isolated. This condition is not something you want to share with everyone. There are only so many times you can say, "I do not feel good." I am very fortunate that I have an understanding husband, but it takes a toll.

**CH** You mentioned not having a firm diagnosis and not feeling validated or certain about the symptoms you were having. You were starting to do your own research. When you were first diagnosed, how did that make you feel and how was the condition described?

**Patient** When I was first diagnosed, I have to admit that I felt like a child at Christmas because I finally had a name to what I had and finally had help. I felt like my gastroenterologist was actively listening to me. When she told me I had IBS-C, all of the symptoms she described were exactly what I was experiencing.

**CH** When you finally received your diagnosis, did you feel that the provider was very confident and did that give you peace of mind?

**Patient** Yes. For the longest time, I thought it was all in my head. I never fully understood that it was the gut and the brain not communicating. I thought it was the food I was eating or something I was doing wrong. When my gastroenterologist explained what was going on, something clicked. I felt relieved that there was help out there.

**CH** When you started treatment with tenapanor (Ibsrela, Ardelyx), what was your response?

**Patient** After taking tenapanor for several weeks, maybe a month, my gastroenterologist asked me how I was doing. I was thrilled and was not having any of the possible side effects she had described when she gave me the prescription. For me, having regular bowel movements 2 or 3 times a day felt like winning the Olympics. She did tell me that tenapanor was a new medication and at first I was a little leery because nothing ever worked or continued to work before, but I have been taking it for approximately 2 years and it has continued to work.

**CH** You have had a positive experience with overall symptom relief. In the phase 3 trials of tenapanor, improvement in overall symptoms occurred as early as week 1 with sustained efficacy through the end of the studies.

The degree of response to treatment should also consider whether the patient has experienced an improvement in their quality of life. What was the drug's impact on your quality of life?

**Patient** I felt like I got my life back. I am able to go out

and travel. Before, I did not even want to leave the house. I feel much better mentally and physically. I am capable of doing things I was not able to do before like yoga and walking.

**CH** How did your provider talk about possible side effects?

**Patient** She told me about the possibility of diarrhea and other side effects. Fortunately, I have not had any.

**CH** Diarrhea is the most common side effect with tenapanor and typically occurs within the first week of treatment. Diarrhea tends to be one of the most common side effects of all constipation medications, although patients may also experience other side effects. It is important for patients to talk to their providers about all of the possible side effects they could experience.

It is also important to remember that tenapanor is indicated for the adult population of IBS-C. It has a boxed warning for risk of serious dehydration in pediatric patients.

What is an important takeaway from your experiences with IBS-C?

**Patient** Living with IBS-C is terrible. Now that I have effective treatment, I would tell other patients not to give up hope. There is help and medication out there. I stayed silent, which probably was not right to do. When you speak to people, it helps because you do not feel alone. While you are having those conversations, you learn that other people have the same symptoms and you can help each other.

**CH** It can be difficult for patients to talk about their symptoms of IBS-C, but once patients find the right provider to share their journey and make them feel comfortable, talking can become easier. Knowing they can put a name to their condition and that there are therapies that can help can give them hope.

*This column was condensed and edited from a Digestive Disease Week presentation sponsored by Ardelyx. The patient was compensated for discussing her experience. Ms Hanson has served on the advisory board/speakers' bureau of Ardelyx, Gilead, GSK, Intercept Pharmaceuticals, Ipsen Pharma, Madrigal Pharmaceuticals, Phathom Pharmaceuticals, Regeneron Pharmaceuticals, Salix Pharmaceuticals, and Sanofi.*