During the Human Practice activities related to inflammatory bowel disease, we have met many patients. We learned a lot from their lives and their voices.

This article comes from the personal experience of a patient with IBD. We recorded and jointly wrote this patient story with his narration, hoping to arouse more people's attention to IBD patients.

Part1

Five years ago, it was December 9, 2016. I was hospitalized for the first time.

The first symptom is my right abdominal pain, writhing pain! At first, I thought I had a bad stomach. Later, after nine months of repeated registration clinic, the doctor could not find out what reason.

Until December of that year, when I was hospitalized, I had a CT scan of my small intestine, which showed thickening of the wall. That's when the doctor told me: your illness is suspected to be CD (Crohn's disease). Having never heard of this disease, I was confused and anxious, so I could only find information about this disease from Baidu. When I was in the hospital, I went from bed to bed, asking other patients about the seriousness of the disease, feeling anxious and unable to accept the truth.

Later, the chief physician told me about infliximab when making rounds. He said that a course of 4 treatments costs about 80,000 yuan, and the last 2 treatments are free. After hearing this, I felt apprehensive. It was tough for an ordinary family like me to afford such expensive medicine and spend so much money.

So, the doctor gave me a combination of hormones and Azathioprine, and I was discharged.

Part2

I was being hospitalized again, which was the most painful experience of my life.

In early January 2017, after lunch at home, I felt my stomach slowly began to ache badly. Struggling with the pain, I took a taxi to the hospital's gastroenterology department. That night, the head nurse got me a temporary bed. This is the second time I've been hospitalized.

The following 15 days in the hospital were the most difficult time in my life and the pain I will never forget.

The fever persists for six to eight hours a day;
The pain was excruciating and intermittent. I was plagued by constant abdominal distress.
Thirteen injections a day, starting from 9 a.m. to about 2 a.m.

Later, my condition continued to deteriorate, and my original weight of 63.5 kg was reduced to 43 kg in the end, basically losing about 1 kg a day. The doctor said it wouldn't work that way. Sooner or later, it would ruin you. So on my tenth day in the hospital, I had my first nasogastric tube.

However, the condition seems to continue to deteriorate. There is no sign of relief symptoms, but it also caused many complications, including pelvic peritonitis, gastrointestinal flatulence, edema, stenosis, urine blood, incontinence, etc. At my worst, I pooped more than 50 times a day.

Part3

"I was 30 years old that year, and the feeling of shame and inferiority is beyond ordinary people's comprehension."

Days of fluids through a nasogastric tube didn't do any good. My intestines are not functioning properly. Instead of absorbing the nutrients, they just drain out. The doctor could do nothing, so he had to put a temporary stool basin on my sickbed.

Every day, I can only be naked, let my mother wipe my body and ass! I felt helpless and self-reproached in that situation, and I don't know how many tears I shed.

I was 30 years old, and that sense of shame and inferiority is beyond ordinary people's comprehension. The people I'm most sorry for are my parents. They've raised me all these years, and they haven't had a chance to enjoy themselves. Yet, I contracted the disease at a young and healthy age. Every time the nurse made the rounds, she lifted the covers and I was naked. That kind of embarrassment, that kind of inferiority, maybe other people don't think what, but my self-esteem let my heart can't accept.

Part4

"It's me who brought the family down."

Night after night, I persisted in suffering the pain. I don't know how many days have passed! The emaciated body is getting worse day by day. The next day the attending doctor shook his head and walked out the door. "Prepare for the worst," he told my dad. As soon as my urine dripped onto my skin thighs, it didn't take long for the skin to fester. When you're feeling vulnerable, it feels like the germs in the air around you are trying to bully you.

I don't know what time has passed. I was so dazed that I couldn't speak, and I had trouble raising my head. One night, I felt like I couldn't go on anymore. I was really tired. At that time, I hope I could have mercy killing and not be so painful. I looked next to my mother in tears. They also did not sleep well for a few days.

When I felt that I could not hold on, my father called the doctor for me. But instead of a doctor, he found a nurse. The nurse did not know how to comfort me, so I whispered to the nurse about my childhood and when I used to be well.

We didn't know each other at all, but she patiently listened to me talk a lot about my past life. I really want to go back to the past, because I'm so tired now! I want to sleep, and I am really tired!

My father and mother burst into tears. I told them I was sorry, that I had brought the family down.

Part5

"I feel as if I had died, but there is hope when things get better."

Since the nasal feeding tube was inserted, my intestines have not been able to tolerate nutrient solution, and my intestines have not been able to absorb nutrients at all. Just when the doctors were about to abandon conservative treatment and remove my stomach tube this afternoon. The condition suddenly took a turn for the better, and the nutrients began to be absorbed. On the second day, the third day and the fourth day, the fluid pressure went from 5 and 10 to 20 and 30 pounds per day! (45 is the amount absorbed by ordinary people)

At 9:00 the following day, Dr. Hu led more than 20 doctors and experts to my bed to see me. When she saw me getting better, she smiled happily, too. Since that day, my bowel movements have gone from 50 to 20 to 10 times a day, and then slowly back to normal. My urine is starting to turn watery, too. Later, when I counted the days, I found that it had already been fifteen days. These fifteen days have been **the most challenging, longest, most painful experience of my life**. I barely slept, and I don't know how I got through it. Maybe it's human limits. I don't know. It feels like I died once.

At that time, it was January 29, 2017, and the Chinese New Year was coming. I had to stay in the hospital for observation for a period of time before I could be discharged, but after the discussion of the doctors, I was sent back to my original place with dozens of boxes of nutrient solutions. I can still remember the warm scene when the doctors and nurses discharged me.

On New Year's Eve, I was lying on the bed in my bedroom, watching the nutrient solution dripping constantly. Families cook a few dishes casually in the living room, which is considered the Spring Festival.

After several months of recuperation, there was no significant change in weight, which was still about 43 kg. Start with three bottles of nutrient solutions a day. I began to drink some porridge soup as the recovery improved. Because there was no taste, I dug two spoonfuls into the porridge soup to stir and eat some. Start with half a bowl of porridge soup, then add a little more each week. The nasogastric solution was reduced from three bottles to two bottles a day, slowly working its way up to one bottle a day. Later, after the gastric tube was pulled out, I began to eat porridge and noodles slowly, and my eating habits could only be cultivated step by step from scratch like a baby.

Part6

"It's been four years, which is not easy, but my illness has gradually stabilized."

Since I was critically ill in January 2017, my condition has gradually improved. But every week still have abdominal pain (intestinal obstruction) about three times; The right belly is sometimes swollen. Six to eight bowel obstructions a month in the second half of 2017. In the first half of 2018, there were four to six bowel obstructions a month.

I didn't eat rice again until May 2018. This is the first time I've eaten rice in a year and a half since I was dying. I didn't dare overeat. I only ate a few mouthfuls, then gradually added portions over the course of a week and slowly returned to my regular diet.

Over the years, I've had more than 200 bowel obstructions. Each episode was as painful as drug addiction, with frequent terror, night sweats and weakness. Every meal after two or three hours after the stomach began to bulge, there are indigestion symptoms and then pain.

Later with experience, each time, I put my fingers into the esophagus, took the food out so as to relieve the pain. If the body is really weak, I will go to a small clinic to inject, strengthen a bit of nutrition.

So far, I have avoided infliximab and have taken one azathioprine tablet a day due to poor financial conditions. It costs 40 yuan a month and 800 yuan a year to take medicine. I think I'd be better off if I got infliximab.

Now I'm back at 110 pounds, working again and learning my driving license. Although divorced last year, I fell in love again this year, hoping everything will going better. I hope to be symptom-free for a year in 2021 and get better after that.

Finally, I want to tell those who are suffering from this disease: this disease is 70% mental, 10% doctor's orders and medication control, 20% diet control. Although we can’t enjoy all the delicious food like normal people, but there are a lot of happy things in life worth loving.

Tips: *Personal experience sharing does not constitute any medical advice. If in doubt, please refer to professional advice.*