

My Behçet's disease journey

The Society has been collecting case histories (people's stories) to use selectively in the media. To encourage more members to offer theirs and to keep you informed of patient journeys, we intend to include some of these stories in the newsletter. If you would like to include something, please contact the admin office on 0845 130 7328 or email info@behcetdisease.org.uk

Very early signs of Behçet's disease started when I was about 6 years old. We had just come back from a short holiday on the Isle of Wight, and I was in bed for about 2 days with a very high temperature and fever and not aware of anything going on around me. The doctor was concerned and thought I might have meningitis, and unless my temperature dropped by a certain time I was to be taken into hospital. Luckily, my temperature dropped and I made a full recovery. I started to get ulcers in my mouth from about the same age; they were always bad and never cleared up quickly, and I just used ulcer pain relievers to ease the pain.

Life went on and by the time I went to high school the ulcers were still coming and going but I was getting used to them being part of my life – they hurt, but I seemed to cope a lot better with the pain and ignored them. By the time I was about 13, I started to have bowel problems, always having diarrhoea and often getting told off for being lazy for not making it to the toilet in time. I had another attack of being unaware of what was happening and high temperature and lost about 3 days, and this time they put it down to a virus.

Everything carried on the same way until I was 22, when ulcers started to appear on my genitals. I went to the doctor, who sent me to the local STD clinic where a doctor examined me and told me I had herpes. My whole world had just fallen apart – I wanted to run away, but I had to tell the people I had been in contact with, which was one of the hardest things I had ever had to do. Life got better. I only had sex when I didn't have any ulcers, and eventually I



Brendan Payne

"It took some 35 years to diagnose my condition, and I feel in the end that I was lucky to find one person who knew what it was."

got married at the age of 25 and had three wonderful children. The marriage didn't last too long, and I moved on and met my second wife. We have been together 19 years now, and she has stuck by me all the way, which is not an easy thing to do.

My ulcers started to get worse and more frequent on my genitals to the point where just to go to the toilet had me crying in agony. Once again I was referred to the STD clinic, where they ran every test and gave me every course of medication they could think of. This went on for 6–8 weeks, but at least I then knew that I was totally clear of every STD. In the end, the doctor took me to another part of the hospital and I saw a dermatologist who took one look at my genitals and my mouth and told me I had Behçet's disease. I didn't have a clue what this was, and at the time no one told me. I was given tablets and

told to see my GP, and that was it.

I suffered on and off with flare-ups, which were controlled with steroids, and the only information I could get about Behçet's disease was on the internet. I was coping with it until 7 years ago, when my bowel problem seemed to be getting worse and I started to bleed from the back end and to lose weight. My wife made an appointment for me the next day with the doctor, who referred me to the hospital as an urgent case to have a colonoscopy. A week later I was at the hospital to have this done, and the consultant could not believe how bad my bowel was. I was admitted, and high doses of steroids were given to me orally as well as in the rectum.

Two weeks on, I was still in hospital with no improvement – in fact I was getting worse. I was sent for another X-ray, and within half an hour the consultant dropped the bombshell that changed my life as well saving it – my bowel was going to be removed at 2 o'clock that afternoon. After the operation, I woke in the high dependency unit to be told that I was lucky to be alive as my bowel had been attacked so badly that they only just managed to get it out.

It took some 35 years to diagnose my condition, and I feel in the end that I was lucky to find one person who knew what it was as otherwise I might not know even now. After all this, I joined the BSS and went along to the hospital at Portsmouth where an open day was taking place and met for the very first time someone who had the same condition as me. I got all the information I needed and a list of people who could help me, and from that time onwards I started to get the care I needed from people that know about Behçet's disease. I wish I had found the Society earlier, but I'm glad I did in the end.

Brendan Payne