

Beth Barker's Story

Beth is now a thriving 21 year old University student, but she has endured debilitating symptoms her whole life. Here, she bravely shares her story with us.

I received my MCAS diagnosis when I was 18, but it was noticeable from birth that I was different to my sisters. I had two febrile convulsions when I was a baby, I experienced high temperatures and bronchitis which developed into asthma at age three. I also managed to break both collar bones before I was four years old.



I struggled a lot at primary school, and I wasn't happy a lot of the time. I found it difficult to concentrate and hated wearing the uniform because it felt so uncomfortable on my skin. As a young child, I would often hold onto my throat as if in pain.



At primary school I experienced extreme joint pain. At 11, I would struggle to get out of bed because my legs were so achy. The doctor dismissed it as growing pains.

I used to do a lot of sport. I was a good runner. I even competed in cross country when I was 11 and came in the national top 20. I would swim three times a week at a local club as well. But by age 13, I was seeing a consultant for chest pains when I was swimming and running. After having scans, they found no issues with my heart, but they did discover I had an irregular heartbeat called Wenckebach.

It was only really in 2017 at the age of 13 when my symptoms became much more pronounced. We had holidayed in America and my dad got a tick bite. He had the red circles on his back which indicated Lyme Disease. I also had a virus. The doctors were worried I had Lyme too and so I was given multiple courses of antibiotics.

These antibiotics caused excessive gut pain. I remember my stomach used to just feel empty all the time and it would also rumble incessantly. It felt like I was constantly hungry. The feeling was just terrible. I went to countless doctors, and they couldn't explain it.

It was during this period I also saw other symptoms, such as excessive sweating, bruising, rashes and insomnia. I was struggling with fatigue, and I was becoming increasingly anxious. It was very frightening for myself and my family.

A year on, my stomach problems had reduced but I was struggling with unexplained chronic headaches.

2019 was even worse. My stomach pain returned while on holiday. My parents and family thought I was exaggerating how painful it was, but it turned out I was severely constipated. I had quit swimming and running that year because I was experiencing too much pain. My mum took me to a nutritionist who diagnosed me with histamine intolerance. The nutritionist also ran blood tests which showed my allergies: horse hair and dust, as well as intolerances: gluten, egg and hazelnuts. The nutritionist diagnosed small intestinal bacterial overgrowth (SIBO).



My doctor did blood tests in 2020 which showed I had inflammation with a positive anti-centromere antibody. I was referred to a rheumatologist who didn't think there was anything to worry about. However, he said my Beighton score was 7/9 so I was hypermobile. My mum then started researching Ehlers Danlos/Hypermobility, and this was the first time I learnt of Mast Cell Activation Syndrome.

All these issues at the age of 16, during my GCSEs year, had really affected my mental health. I was diagnosed with depression, anxiety and ADHD. I started taking an anti-depressant called sertraline, which helped. I had a good summer and felt more confident about going into sixth form. However, my gut pain and joint pain persisted, and nothing seemed to help with these symptoms.

Moving forward into 2021, I still had terrible joint aches, gut pain, and my mental health was suffering. I was so scared the unbearable discomfort I had experienced the year prior would return. I saw a rheumatologist privately and he diagnosed complex regional pain syndrome. I was extremely depressed at this point, suffering from panic attacks, anxiety and suicidal thoughts. I started seeing a psychologist.

Through the summer of 2021 into 2022, I increased my sertraline, and my gut health improved slightly after I saw several more gastroenterologists. I was doing well in my A levels, and I received an offer from my dream university. Everything seemed to be going well! I was improving and I was feeling happy.

Three months before my A levels, I took an ibuprofen tablet on an empty stomach because of an ear infection and I became very ill. Luckily, I sat my exams and got my place at university, but I had to postpone it for a year because I was in so much pain. I saw numerous doctors who couldn't explain the pain. One gastroenterologist did an X-ray and found I had a slow bowel transit, diagnosing me with chronic idiopathic constipation. He started me on medication but that made me feel more unwell, and even more hopeless and depressed.



During my gap year, my Mum consulted an immunologist who was a Mast Cell specialist as she was convinced I had this. The immunologist did various tests. He confirmed I had MCAS. He put me on antihistamines which I still take daily - loratadine and famotidine.



Before taking medications, my symptoms were: rashes, tummy pain, cold feeling, itching, feeling a pulse in my abdomen, rumbling pain, spasms, feeling 'tickles' in my body, headaches, joint aches, chronic fatigue, backache, depression and anxiety. The antihistamines helped, and over a period of 6 months, my symptoms improved to the point where I had very little gut pain or joint pain. I now joke with my mum that my antihistamines are my magic tablets because they have helped so much.

In 2023, my GP referred me to University College Hospital in London and I was diagnosed with hypermobility and incomplete Marfan syndrome. They recognised my sensitivity to different medications and would prescribe medications accordingly.

When I started university in 2023, I was in a better place. Now in my second year, I'm lucky to get quality low-histamine food in college, which is vital for managing symptoms.

Things aren't perfect—I still struggle with MCAS symptoms like itchy skin and fragrance triggers. My constipation has improved, but I now react to laptops with throbbing headaches. I also have very painful periods, spending most of the time in the bathroom. A gynaecologist suggested a mast cell stabiliser, so I'll be starting ketotifen and a DAO supplement soon, hoping they help with headaches and period pain.

I am so grateful to all those doctors and consultants who believed in the pain I was experiencing and took my symptoms seriously.