

INSIGHTS



Family reflections: spend a day in my son's shoes

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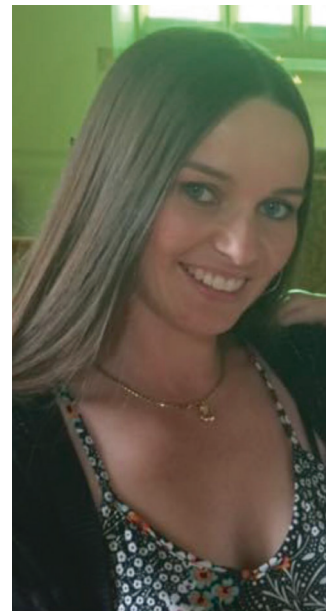
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My son JJ, who is 13, started having symptoms of Crohn's when he was just 4 years old. For the following 3 years, they were quite sporadic, so the doctor initially diagnosed him with irritable bowel syndrome. However, by the time JJ was 7 years old, the symptoms were happening daily and there was no let up from them. He was going to the toilet up to seven times a day including in the middle of the night when he'd be shut in the bathroom for up to 3 h at a time.



He used to sit on the toilet screaming and nearly passing out with the pain, and the blood that he passed with this stools was just atrocious. The toilet pan would be full of it. He had classic Crohn's ulcers around his mouth and his gums were bleeding. His belly was all distorted, one side sunken, the other distended. He didn't grow like other kids—so much so he could wear the same size shoes from Reception to Year Three. During this time his

height increased by less than a centimeter. He was always tired and falling asleep.



It's really hard to be different at that age. Before the diagnosis JJ had a teacher who didn't understand and was awful with him. The teacher used to say to him, "No you've already been to the toilet once you do not need to go again." And JJ would be coming home in agony saying, "I had to hold it" and of course that made the pain so much worse. You can't really fight the teacher as a child. Once he was diagnosed the school was made aware, everything changed for the better.

In the end, I went down to the GP with a video of JJ on the toilet, and its contents in a bucket—which is when the doctor agreed it looked like Crohn's disease and referred him for a colonoscopy.

After the diagnosis he went on a Modulen diet for 6 weeks and he went up three shoe sizes, six inches in height and put on a stone in weight over the summer holidays. Then he moved to a cinnamon and benzoate-free diet with Fortisip milkshakes and VSL#3 powder, which contains live gut bacteria.

JJ still experiences diarrhea, stomach aches and flaky skin, and combats these through exercise, drinking lots of water, and a special diet from the GP.

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However, in order to really understand what JJ's life is like, we'd love it if researchers tried the Crohn's & Colitis UK app In Your Shoes, which gives you prompts all day to eat an IBD diet, visit the toilet up to 20 times, experience fatigue and other symptoms ([In My Shoes | It Takes Guts](#)).

There is no known cure for Crohn's or colitis, and finding one is the ultimate goal. However, as JJ is just entering his teenage years, looks are becoming important. He's not quite old enough to grow a beard to hide the Crohn's sores on his face, which sometimes look like he has sauce or ketchup around his mouth. He feels people looking at him, making him self-conscious at an age when you're already sensitive about your looks. If research could develop something that could control the sores, it would make such a difference.

Medicine to relieve his pain would give him back normality so he can get through a day like everyone else. This would free him from that fear constantly in the back of his mind every time he goes out that the agony may kick in without warning. He still goes out, but it does take a mental toll.

Once or twice a week, he will walk around with a pain level of six or seven out of ten. It's become his norm. It spreads down his left side and across the bottom of the abdomen, and lasts an hour or so at a time, or perhaps until he passes wind. He can cope with it and still go to karate. However, he does tend to be better the more he exercises.

He masks it well and most people would not know he was worried. What they don't know is he checks the calendar every time before deciding what to eat—if he doesn't have a trip or karate practice, he may come off his diet and try something new. He just had a Greggs chicken bake for the first time and it was a big success!

JJ is quite determined, and as a mum I worry he will face issues as he grows up, though I'm not sure what they will be. I know he will continue to battle fatigue and pain, which makes me wonder if his condition will ever affect his career choice. Right now, he wants to be a PE teacher. When he's having a flare up, a part of me questions whether that will be possible for him. I'm just thankful he manages to get to school every day.

I did used to wonder how the Crohn's would affect him in terms of dating and relationships but at 13 he's already so charismatic, I've lost any concerns on that front.

Our diagnosis journey was very tough, and with the pressures on the NHS only increasing, a quicker, cheaper test to detect

inflammatory bowel disease is a must for the children who come after JJ. A finger prick test to pick up IBD would be a dream.

However, when I ask my son what his biggest issue is, he straight away brings up the taste of the medicines—particularly the Modulen milkshakes and the VSL powders. There was definitely a gap in considering the experience of the patient when developing these medicines, and I don't know if making them as cheap as possible overrode all other considerations. However, they clearly forgot that while an adult can rationalize drinking something that tastes disgusting, it can be quite traumatic for kids—and the parents who feel they're forcing an unpleasant experience on their children. Luckily for me, JJ is older than his years, and is switched on enough to know it's gross but gone in 30 s, at which point he can get on with his day. Having said that, the only way you can get him to tolerate it is by mixing it with Vimto squash, which annihilates the taste of it. With all the sugar in it, that is not the best thing for his health.

In the wider, social research world, the lack of awareness that young people can have inflammatory bowel disease really needs to be tackled. JJ was once told that Crohn's was "an older person's disease". Evidence showing prevalence of IBD among young people needs to be done, and publicized on a national scale, to encourage earlier diagnosis, as well as greater acceptance of these conditions among the general public.

Lastly, I'd say thank you to all the researchers in this field for everything you've already achieved. The whole healthcare pathway has come such a long way, even in the time we've been dealing with it. Just please remember that there are children with these conditions as well so maybe when you next develop a medication you can bear in mind the tastebuds of the younger generations too!

ADDITIONAL INFORMATION

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