

## Lorraine - Patient Video Transcript

My name is Lorraine and I started work in a science lab before moving into management in a hospital unit. It was a job that I loved and it was exciting because it brought science and medicine together. Unfortunately, Crohn's took its toll on me and I was medically retired 10 years ago.

I was diagnosed with Crohn's disease back in 1978. I had had intermittent bouts of stomach aches and diarrhoea since I was young, I got detention at school for going to the toilet during lessons because I couldn't tell the teacher that I had diarrhoea! It got much worse in my 20s and I went to the GP on numerous occasions. I was feeling very low because I couldn't understand what was happening to me, this went on for about 2 years.

I had two little girls, 7 and 3 years old and a very patient husband and it was thanks to him that I was finally referred to the hospital (he'd telephoned my GP) as I was having a bad flare up at the time. I had to have a laparotomy and was subsequently put on steroids. These helped me by reducing the inflammation and increasing my appetite, but they affected my moods and made me gain a lot of weight. This was the start of a long, painful and often isolating road. I've had quite a lot of surgery since and although it relived the painful symptoms of the narrowing of the bowel it made the diarrhoea worse. I've had to have many different medications, but in 2006 I started Biologic drugs, first Infliximab and then Humira and since then the flare ups have been far fewer and I have felt a lot better.

I found out about the Boost programme at St Marks hospital at an outpatient appointment. I was asked if I'd like to take part in a focus group discussion with other people who had IBD. It was amazing to hear their stories and as someone who has had Crohn's for so long I could feel their pain. The focus group was the first step in the development of a new self-management program where patients have more involvement in the management of their own condition. I found this approach new and refreshing, so I had to find out more.

The Boost programme is opening a whole new field of possibilities for the patient. In the time I've had Crohn's I've witnessed many changes in tests and treatment but very little in self-management. I can see what a huge benefit BOOST will be for patients, as it is a very lonely road out there when you are first diagnosed. This will be a great tool in learning to accept that with some extra work we may be able to go about our daily lives and gain some semblance of control. Our peers are getting on with their lives with very little concern and they can eat what they want, when they want, we to have to be careful and learn what upsets us and take loads of medicines, this places an enormous strain on us.

A big amount of research has been done to find a cure and manage IBD with medicines, but through this innovative research I hope that people using this programme will feel that this new tool will become as necessary as taking the medicines.

I wanted to take part in the development of the Boost programme because there is a huge gap between hospital and home. Learning about the needs, responses and practical implications of having such an embarrassing condition can only help. Managing pain, fatigue and urgency can at times seem impossible, but with careful understanding and planning one can use strategies that help us to continue with daily life so that symptoms have a less negative impact.

I've been attending group discussions to develop the Boost online programme, in which I have voiced my opinions at the style and content of the sessions. Throughout this process I felt that I was working with a research team who are striving to provide a new and innovative way of helping us. Most importantly it would be wonderful to give people using this programme control over their daily lives again.