

Communicating your IBD

A Personal story of Communication

If you are not open with yourself about your IBD how can you expect to communicate about your IBD with others? It is important that you be honest with yourself.

You must try to come to terms with your IBD and accept it. Don't down-play your symptoms, but also, don't over-dramatise them. Nor must you beat yourself up about your IBD, and everything associated with it – go with the flow.

If you are newly diagnosed, take some time out to get your 'head around' your diagnosis; to help in this, give yourself a framework to work in. For example:

- Prepare for any appointments with your healthcare practitioner: make a list of what you want to ask him/her, and prepare properly for your consultation – this will help you communicate with your doctor
- Think carefully how you want to communicate to others. Start to think about trust, and deciding when/how to tell others
- Try not to become 'The Expert', feeling that you have to explain to others what your IBD is all about.

Take your time, get your thoughts in order, decide what you want to say, to whom, and when. Of course you will worry, but if you do, talk to other people within your network. Don't bottle things up.

This is the experience of JS, a 28 year old female who was diagnosed with Crohn's at the age of 21

Prior to diagnosis I had been suffering with symptoms for about 12 months. They started off mild, but over time increased in severity and interference in my life. I told my parents about some of the symptoms, as they were the visible ones (weight loss and chronic fatigue). My mood also altered during this time; I was very irritable and seemed to be in bad form all the time.

During this period the symptoms also started interfering with work and college. I was working part-time in a department store and studying a full-time course in college. I didn't confide in any of my friends at this time as most of the symptoms were invisible to anyone looking from the outside. Eventually I went to my GP [physician]; we began with looking at food allergy remedies. I started a food diary and tried different diets that excluded certain food groups – dairy and wheat, but my symptoms didn't improve. I changed my GP (he had treated my grandparents and my parents, so he knew the family). He referred me to a gastroenterologist.

At my first consultation I took my mother with me. After listening to all my symptoms, the gastroenterologist ordered an endoscopy, colonoscopy, blood tests and barium meal test.

It was during this time that I told my employer. I simply sat down with my manager and explained that I hadn't been feeling well (they knew as I had gone home sick from work on a few occasions), and that I was undergoing tests for Crohn's disease. I explained that I couldn't keep working the same hours and go to college at the same time while feeling like this – and that college was more important at this time. They were very understanding and agreed to give me 3 months off work to concentrate on college and getting better.

Once the diagnosis had been made, I met with the college. I explained to them that I had been diagnosed with Crohn's and this was why I had missed a lot of classes. They were less sympathetic than my employer – but I did finish college and went back to work.

At this time I also confided in my close friends. Now that I had a name for what was happening to me I could explain it to them; a lot of them told me afterwards that they had thought I was anorexic. I simply told them what I knew about the disease – and that there was no cure. All my friends were very understanding and wanted to find out more about it. There was never any trouble when I explained to them that I couldn't go out, or had to do different things as I wasn't feeling good. In fact most of the time they changed plans to include me.

Through taking my medication, and regular visits with my GP for blood tests, I managed to live virtually symptom free for 3 years. But then all the symptoms started coming back again. It was during a particular bad flare up that my gastroenterologist recommended surgery. **After a lot of discussions and a consultation** with the surgeon I decided to go ahead with it.

By this time I had changed jobs. I had told my new employer about my condition, but I hadn't gone into great detail with them as there was no need at the time as I was in remission. **Once I knew I needed the surgery, I sat down with them again and explained the situation to them.** I simply told them that I was out of remission and that the disease had caused a lot of scarring on my parts of my intestines. As a result they were not working they way they should and the damaged bit was going to be removed by surgery. I told them that I would need 6 weeks off work for surgery and recovery, but after this the statistics were good about going into remission for up to 5 years afterwards. After talking with them, we agreed on a time that would suit: again my employer was very understanding and obliging.

During all this I did have a long-term boyfriend who I found it more difficult to communicate with. I told him the same details as my friends but found it very embarrassing going into the finer details of it all. We broke up before the surgery, but he did come to visit me afterwards. The first surgery was a success in so far as they managed to do the resection, but I didn't remain symptom free for long. About 2 months after the surgery, I started getting severe pain in my lower right quadrant so I went back to the surgeon. The pain reached such a level that I had to take time off work. I wasn't eating as the pain wasn't worth it.

My studies were also suffering and my exams were just around the corner. **I told my new college about my Crohn's** and they were much more understanding and supportive than my first college had been. I sat my exams but ended up in hospital afterwards. The pain had got so bad that I couldn't even get out of bed.

I was admitted into hospital and remained there for over 8 months.

It is now August and I'm delighted to say that I'm well on my way to recovery. My appetite has returned, my weight has stabilised, I am no longer anaemic, and more importantly my Crohn's disease is in remission. I am hoping to return to work soon, as well as continue with my studies. Communication during this was time was crucial to my recovery. **I had built up a support network** in my family (mother, father, two brothers and one sister). They visited me every day and were there to listen to and support me during the very hard times.

I also have three very close friends who I confide in. They were also there to offer their support. I can, with my hand on my heart, say that I would not have got through this as well as I have without them all. It is vital that you have someone other than medical professionals to confide in to keep you smiling – and sane!!

I have also started a new relationship and my new boyfriend is very understanding and encouraging. After I had told him about my illness, by the next time we went out, he had looked things up on the internet, and was able to talk to me about what was happening to me in an open and supportive way.

My advice about communicating about your IBD

- You need to talk to people
- You need to build yourself a support network
- I should have taken my symptoms seriously much sooner, talked about them and sought help earlier, rather than just living with them and ignoring them
- I didn't communicate with my body: I worked through the symptoms/pain when I should have been in hospital
- Take your symptoms seriously. They don't go away by themselves. You need treatment and you need help and support – and for that you have to be able to talk to people, whether that is your doctor, your family, your friends or your IBD nurse.