A Broader Scope

One Patient's Experience

BY Anny Dupéré

In May 1998, I had 65 cm removed from the latter portion of my ileum due to Crohn's disease. This was accompanied by the insertion of surgical drains that I had not been informed of, and I received no general information about my post-operative wound care. In order to assist you in understanding a patient's perspective, I would like to share my story.

I had been severely ill and mainly bedridden since the beginning of 1997. My symptoms had begun as far back as 1992 and I spent the greater portion of my 20s in the hospital emergency room. I was repeatedly sent home without answers, wondering if I was losing my mind. I had none of the typical red flags of the disease and therefore was overlooked as a Crohn's patient with potential complications.

Diagnosis: Crohn's

After wasting away from 57 kg to 41 kg and eventually to 35 kg, I was diagnosed with severe Crohn's disease. The damage to my small intestine was immediately visible via a colonoscopy. Ironically, this was my first scope, despite many years of suffering and a vast family history of Crohn's disease. To complicate matters, I had always suffered from predominant pain on the lower left portion of my abdomen, which up until my surgery had only confused doctors even more. This pain resulted from a life-threatening abscess hidden on my bladder. Despite the pain, and after many scans, there was no indication of the presence of an abscess nor of a fever. The cause was only discovered during my resectional surgery, along with the finding of a loop in my bowel.

A "rude" awakening

I had been informed of the actual surgical procedure, but feel that I was left in the dark regarding the post-op reality of this type of medical intervention. I awoke to several unexpected tubes, a drain from the site of the surgery, a catheter, the epidural tube, my I.V. and a heavily bandaged wound. I had been only briefly informed of the aftermath, and this wound drain was not included in my expectations. I felt like my body no longer belonged to me and I perceived myself as a slab of scientific matter. Furthermore, my drain was connected to a bottle with its contents quite visible to the curious people passing by. I was not expecting the recovery to involve so much lying down due to extensive bleeding or for it to render me completely dependent on others.

I was not prepared for the precise care involved with the actual wound incision. Why hadn't they placed the drain/catheter containers in a more discreet place? Why was I not informed of what was involved in my post-operative wound care? Why hadn't they forewarned me of the horrible side effects from medication and the surgery that were to come? Why had they told me that my scar would be barely noticeable — a "bikini" scar, as they had put it?

Despite these complaints I also had certain positive experiences, such as meeting a fantastic gastrointerologist, being treated very humanely by medical staff and learning the most important lesson of all: no matter what, always trust yourself and listen to your body. No one knows your body and your health better than yourself.

If I was to give one piece of humble, non-scientific advice to medical practitioners it would be: continue to trust science, but never forget to trust patients — often they have key insights and a broader scope on the reality of their own health.

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