

PRACTICE

A PATIENT'S JOURNEY

Ulcerative colitis

A student in her 20s recounts her complicated journey to a diagnosis of ulcerative colitis. As her symptoms progressively worsened, she overcame her embarrassment and sought further help in reaching a diagnosis

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This is one of a series of occasional articles by patients about their experiences that offer lessons to doctors. The *BMJ* welcomes contributions to the series. Please contact Peter Lapsley (plapsley@bmj.com) for guidance.

I remember being mortified at the thought of seeing a doctor about a prolapsed haemorrhoid at the age of 23. My journey had started in the summer of 2007, in central Asia, while I was on a university work experience programme. For over a month I suffered from constant diarrhoea. Everyone around me explained that this was a normal part of travelling and that I should try and see the funny side. However, I found the symptoms intolerable. On my return to the UK a month later, my general practitioner sent a sample for microbiology, which came back positive. I was prescribed a single dose of antibiotic and the diarrhoea improved.

However, over the following year (my final year of undergraduate studies) I was never quite right. But I took too long to back to a doctor about my bowel problems. By the time I went to my GP in February 2009, during my MSc course, I had been passing blood and mucus for about three months. My delay in seeking further medical help was caused by the gradual and intermittent onset of the symptoms and, of course, by my own embarrassment.

When I went to see my new GP she sent me for blood tests, which showed raised inflammatory markers, and referred me for a flexible sigmoidoscopy. I had gradually become more and more exhausted and everyday activities were requiring increasing amounts of stamina. During my first degree I had been a keen member of the hill walking club and had walked 10 Munros in a weekend; now a walk to the supermarket was a struggle. I went back to see my GP and explained that I was finding things very difficult, my abdomen was distended, and my friends had told me I had turned grey. However, she said I should wait for the flexible sigmoidoscopy at the hospital.

A couple of weeks after seeing my GP, while I was at home in the house I shared with student friends, it felt as if my bowel had prolapsed. I was then in the very unusual situation of having to explain this to my new boyfriend. He insisted on having a look and, not being a doctor, decided it looked like a large prolapsed haemorrhoid. On seeing my toilet bowl filled with blood and mucus, however, he took me to the Saturday drop-in medical centre. I remember being mortified at the thought of seeing a doctor about a haemorrhoid and I put a full face of make-up on in an effort to make myself as attractive as possible.

In the accident and emergency department attached to the drop-in centre, the doctor took my history—I explained the raised inflammatory markers and the suspected inflammatory bowel disease. He did a rectal examination, which was incredibly painful, misdiagnosed an anal fissure, prescribed Anoheal (diltiazem hydrochloride 2% cream), told me to chase up my flexible sigmoidoscopy, and discharged me.

At this point I felt incredibly helpless and could feel myself fading away. My boyfriend put me on a train to my parents and I stayed there for the rest of the weekend. I spent Sunday on the sofa and tried lying on my front on the floor to stop myself from going to the toilet because it was so unbearable. On the Sunday night I remember passing a continuous stream of blood for four seconds. I could hardly move after this and struggled back to bed. In the morning my mother came in to see me; she later told me that for the first time she had realised what the critical care nurses meant when they said a patient was “going off.”

My mother took me to the accident and emergency department and I was sent in to see a doctor immediately. The doctor ordered a full body x ray, admitted me to acute medical care, and put me in the hands of the gastroenterologists. By this time I was so weak that I could hardly lift my arm and needed all of the electric features on the hospital bed. That afternoon I was diagnosed by a consultant gastroenterologist as having ulcerative colitis and was prescribed intravenous steroids. I was finally in safe hands, where I needed to be, and getting treatment.

Difficult hurdles

Ironically, receiving the diagnosis of ulcerative colitis was not one of the difficult points that stand out in my memory. I was so happy to be in hospital that the diagnosis paled in comparison. After three days in hospital my condition had completely stabilised, in rather a miraculous fashion. However, after I had left hospital and as my steroid dose was tapered down, the ulcerative colitis relapsed and I had to go back into hospital for six days of intravenous steroids. This was certainly a low point as I came to understand the chronic nature of my illness.

Being prescribed azathioprine and reading the patient information leaflet one night in the hospital was another low point. The leaflet stated that a common side effect from azathioprine was cancer. It suddenly sunk in how serious the condition was if I had no choice but to take this cytotoxic medication every day for the foreseeable future. However, six weeks later I began projectile vomiting, so the azathioprine was swapped for mercaptopurine.

The next difficult step was when I started to lose blood again, in September 2009, despite being on mercaptopurine and a low dose of steroids. I spent the week before a flexible sigmoidoscopy in a terrified state, fearing that I would need a colectomy. However, the sigmoidoscopy showed only mild localised inflammation.

One of the most difficult things of all was taking steroids for eight months: in the end I was desperate to come off them. I had put on a huge amount of weight and my face had changed so much that even close relatives did not recognise me.

The immunosuppressive cocktail of medication that I was taking added another equally difficult hurdle: the proliferation of tiny plantar warts on my face. I first went to my GP when I had one wart, but this was not recognised and by the time I went back I had over 10 warts on my face. This was the final straw. I had gone from being a sporty young woman to one with a huge round face with warts on it. Cream treatment and cryotherapy provided some benefit but did not remove the one original and very stubborn wart. Laser treatment was not approved for me and the only remaining option was cautery and curettage. Appalled at the thought of someone taking a scalpel to my face

I went to a private clinic and had my warts removed by radiosurgery, a novel and unusual treatment I am told, but one that worked excellently and has left me without scars.

Looking forward

It is now three years since I was diagnosed. The mercaptopurine, mesalazine, and occasionally a rectal prednisolone foam have more or less kept the ulcerative colitis under control, although it is worse when I catch a cold, which happens more often as I am immunosuppressed.

It has been an adjustment learning to live with a chronic illness, learning not to push myself (contrary to all that training in the Scottish highlands), and taking rest when it is needed. The condition is debilitating, and in some respects the term "disability" fits it better than "illness," although describing myself as disabled is something that I still have not come to terms with. The inflammatory bowel disease specialist nurses provide an excellent service, and expert help is only a phone call or an email away.

I am now in my third year of a PhD in a laboratory researching the production of recombinant proteins in mammalian cells. Although my symptoms are managed so that I can live my life, flare-ups still occur from time to time, which are short lived and do not require admission to hospital but do necessitate time out of the laboratory. If my ulcerative colitis did relapse significantly I would like to think that monoclonal antibodies would be offered to me before a colectomy.

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Late diagnosis

My journey to diagnosis was not a smooth one, and I have spent many months wondering how and why I almost bled to death in a student house. Some of the factors that I believe contributed to my late diagnosis are listed below.

- My symptoms did not quite fit the textbook
- The pain I experienced outside the bathroom was an intermittent, dull ache and I remember describing it to my GP as not being as bad as period pains
- As a hill walker, I had learnt to keep going and push myself and maybe this attitude did not help me to help myself
- Ulcerative colitis has a very low media profile so I was not able to self diagnose and I thought it was irritable bowel syndrome
- Some of the doctors I saw did not realise how severe ulcerative colitis could be and had experience of dealing only with mild forms of the condition
- At the time of onset of symptoms I did not have an established relationship with a GP, and between onset and stabilisation of the colitis I lived in four different cities, so having to overcome embarrassment to see new doctors all the time was difficult
- The toilet in one of my student flats had a dark bowl and was poorly lit
- I hid my grey face and embarrassment with make-up when I went to the accident and emergency department for the first time

A doctor's perspective

Ulcerative colitis is an inflammatory disorder of the colon, leading to bloody diarrhoea. It has a prevalence of about 200 per 100 000 population and often presents at age 15-30 years. The inflammation begins in the rectum and is continuous, extending along the colon for a variable distance. The cause is unknown, but a disordered immune response to a luminal agent, probably commensal bacteria, is the likely mechanism. Smoking is protective, and it is not uncommon for symptoms to begin soon after stopping smoking. Ulcerative colitis often has a remitting and relapsing pattern of disease activity, though continuous symptoms of varying severity are also common.

Diagnosis is usually straightforward, with typical appearances being evident at initial mucosal inspection, often by sigmoidoscopy. However, such patients have to reach a gastroenterologist first, which is not as easy as we might think.

Patients are often embarrassed to talk about their bowels and may put up with symptoms rather than seek help. Delays can also occur when blood loss is less of a feature or is erroneously believed to have its origins in the anal canal. Such patients can be labelled as having irritable bowel syndrome for a considerable length of time. This may then be compounded by incomplete or inaccurate assessment at the initial contact with medical professionals, which seems to have happened with this young woman.

I believe that as gastroenterologists we are mindful of how inflammatory bowel disease can affect our patient's lives. They often present at a time when they want to be getting on with their lives and careers, only to be knocked back by the morbidity that can come with colitis, the need to take regular medication, and the label of having a "chronic" condition. At times I think we can underestimate the impact such an illness can have, perhaps particularly as it is something we see all the time. This young woman's journey demonstrates a huge impact on her life.

At diagnosis an explanation of the condition, treatments, and expected progress are important. Our inflammatory bowel disease nurses are helpful at this point and have more time than doctors to discuss this and explore patients' perceptions and concerns.

Many patients do well with oral and topical mesalazines. Those who need more than one course of steroids are offered immunosuppression with thiopurines. These agents are usually well tolerated but can cause problems. When we suspect that patients may need to step up their treatment we discuss these drugs with them and give them lots of information, in the form of leaflets and website resources. This case is a reminder of the shortcomings of the patient information leaflets in medication boxes. They can be at best unhelpful, woefully out of date, and not relevant to many of our patients.

Ulcerative colitis is a chronic condition and most patients need to take treatment daily. This can act as a negative daily reminder that they have such a chronic condition, and at times it may be difficult for them to see any light at the end of the tunnel. Our specialist nurses play a pivotal role here, being a prompt point of contact for patients with such concerns, for advice about relapses, not responding to initial stepping up of treatment, or indeed any other problems. Patients really appreciate help being readily at hand, by phone or email, and value the extra time our nurses can give them.

Biological treatments such as infliximab and adalimumab have transformed our management of Crohn's disease, but their exact role in ulcerative colitis is unclear. They are likely to be useful, but better studies are needed to confirm this, as recent studies of these agents in ulcerative colitis are flawed and have resulted in funding agencies restricting access. This area needs urgent attention, particularly as the only alternative may well be a colectomy.

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