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# CASE STUDY: ULCERATIVE COLITIS (IBD)

***The impact of IBD on the nutritional status and life of an 18 year old***

**Part 2: Post-surgical experiences, diet with an ileostomy and the ileoanal pouch**

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Part 1 of this article can be found in *NHD Magazine*, April Issue 113

## Case Study *Part 2*

*It was dark, she had no idea what time it was. For a minute, she wasn't sure where she was, but it all came flooding back. Lying in a bed, propped up a little and surrounded by beeping machines. Wires and tubes to the left and right of her. The cannula in her left hand pulled a little as she tried to scratch her nose. Looking around the room, she felt a similar pull in her neck. Another cannula in the left of her neck. It made her shiver a little. Remembering why she was there, she patted her abdomen, expecting it to be tender. No pain, nor discomfort, just the rustle of the new ileostomy bag and the large white dressing on her surgical wound. The nurse came in, 'Well hello, you've been sleeping. Don't you worry; we'll get you back on your feet in no time'. Maria smiled and nodded off again . . .*

Maria stayed on the High Dependency Unit for three days after her surgery (a restorative proctocolectomy with ileoanal pouch construction and temporary ileostomy; see Part 1 of this case study in NHD April 2016, for more information about this procedure). In the weeks preceding the surgery she was introduced to a specialist stoma care nurse who explained the surgical procedure to Maria and her family. She was able to answer the many questions Maria had about life with an ileostomy. What will it look like? Will she feel it? How big are the bags? Will it smell? The list went on. Following her surgery, the stoma care nurse reviewed Maria on the ward and after a few days, as Maria was able to get up and walk around, she went through changing the bag and how to care for the skin around the stoma. In the few days following the surgery, Maria hadn't been eating well, therefore her stoma output had been limited. However, as she gained her appetite back, she found many foods resulted in higher outputs than others; for example, high fibre cereal and fruit. In addition, the effects of some foods were particularly malodourous and this was not pleasant. For the first five days post-surgery the output was quite liquid. However, the consistency improved and could be described as toothpaste or porridge consistency (type 6 stools7). Initially, the bag required emptying every two to three hours, but as things settled over the week following the surgery, this reduced to approximately three to four times per day. Please see Table 1 for an overview of some of the dietary considerations with an ileostomy.

As Maria's weight had dipped to 45kg (BMI 16.3kg/m2) prior to surgery, she was referred to the dietitian by the ward nursing staff. She was prescribed 3 x 220ml milkshake style, 1.5kcal/ml oral sip feeds per day. Maria initially struggled to consume all three of the sip feeds each day, but once she was discharged home, this became easier and she continued to take them for approximately three months. She made the decision herself to discontinue them as she was

Table 1: Dietary considerations with ileostomies

| **In the main, most people with an ileostomy can manage a normal diet.[1] In the first few weeks after surgery, most patients require a low-fibre diet. A high-fibre diet can increase the size of stools, which can cause the bowel to become temporarily blocked. After around eight weeks, a normal diet can be introduced.[2]** | |
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| Reintroducing foods | A healthy, balanced diet, including plenty of fresh fruit and vegetables (at least five portions a day) and wholegrains, should be encouraged. Patients may reintroduce new foods slowly after surgery. There may be long-term anxiety around eating some foods, especially after many years of avoiding them due to GI symptoms. Introducing at the rate of one new food at each meal may be agreeable. This will allow patients to judge the effects of the food. Keeping a 'food/symptom diary' may be useful. |
| Wind/flatulence/bloating | Some foods may cause wind, e.g. beans and pulses, brassica vegetables, onions, nuts and eggs. Fizzy drinks and beer also cause wind. These may be best avoided or kept to a minimum. Fennel and peppermint tea may help to reduce wind. Skipping meals may make the problem worse.[2] |
| Malodourous/smelly stools | Some food may create malodourous stools, e.g. fish, eggs, spiced foods, cabbage. Many people worry that their bag will smell. However, all modern appliances have air filters that have charcoal in them, which neutralises the smell. Special liquids and tablets that are placed in the bag are available to reduce any odour. |
| Diarrhoea | A high fibre intake, spicy or fried foods, alcoholic or caffeinated drinks may cause diarrhoea. Fruit juices, fresh or dried fruits, vegetables and salads are also possible causes. Some sweets and cakes are sweetened with sorbitol. This may have a laxative effect for some patients. Some patients may still require antidiarrhoeals to manage loose stools. |
| Dehydration | As the re-absorb of water and minerals within the large intestine is now absent, there is a greater risk of dehydration. A good fluid intake is advised, particularly in hot weather or during activities or sports. Rehydration powders my help to reduce dehydration. |
| Undigested food | Soft, well-formed stools are usually formed in the large intestine. In its absence, patients may experience looser stools containing undigested foods, such as, sweetcorn, peas, mushrooms, apple, carrot etc. These are generally harmless, but patients should be advised to chew these foods well and even slitting the skins/kernels on peas and sweetcorn. Rarely, these foods can cause a blockage of the stoma. |
| **Foods to improve symptoms** | |
| To reduce output/improve stool consistency | Cheese and yogurt<br>Mash potatoes, boiled rice or pasta<br>Marshmallows or Jelly babies<br>Creamy peanut butter<br>Ready Brek or porridge<br>Toast half and half/ 50:50 bread may be better tolerated<br>Apple sauce/cooked apple<br>Ripe banana |
| For nutrition support | Full fat milk - aim for one pint per day in drinks or added to food.<br>Add extra olive oil or margarine to meals.<br>Eat little and often - aim for six small, high calorie meals and snacks per day.<br>Encourage milk puddings such as sago, semolina, yoghurt or rice pudding.<br>Encourage milky drinks such as hot chocolate, Ovaltine, Build-Up or Complan, or prescribed sip feeds. |

eating well and felt that the sip feeds were dampening her appetite. For almost nine months, Maria had her ileostomy. She gained 5.0kg in weight and her BMI increased to 18.4kg/m2 (weight 50kg, height 1.65m). The ileostomy had given her a new lease of life. She was free from abdominal pain and her appetite had improved significantly.

During the time with her ileostomy, Maria was able to introduce a fairly normal and healthy diet. She was managing five portions of fruit and vegetables per day and some higher fibre foods, such as Weetabix, wholemeal bread and baked beans. She avoided highly spiced foods, fizzy drinks, alcohol and some vegetables such as celery, sweetcorn and onions, as these caused her excessive wind and looser stools. She was more energetic and she was able to sleep well, which made a huge difference to Maria's general wellbeing and allowed her to take on a few hours of volunteering work at a local charity shop. Although she remained self-conscious about her health issues and her ileostomy, she was able to engage in social events with her peers and family.

Nine months on with her ileostomy, Maria was reviewed via a water-soluble enema and ultrasound scan (loopogram)[3,4] to ensure her ileoanal pouch had healed and she was suitable for the reversal of the ileostomy. This procedure showed that the pouch had healed and Maria was booked in for her ileostomy reversal two weeks later.

Following the reversal operation, Maria returned to the ward. She was anxious and elated at the same time. In many ways, she was pleased that the ileostomy was reversed, but she was concerned that she would be passing stools via her anus for the first time in nine months. Again, she had so many questions rush through her head. Will she have continence? Will she be in pain again? What if she can't control her bowels? Her stoma care nurse was able to answer some of these questions.

Table 2: Complications in UC and ileoanal pouch patients

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| Toxic megacolon | A rare but serious complication of severe ulcerative colitis.<br>Inflammation in the large intestine becomes swollen due to trapped gas caused by inflammation.<br>It can cause a sudden drop in blood pressure, resulting in shock.<br>The bowel can rupture and septicaemia can occur.<br>Symptoms include abdominal pain, pyrexia and tachycardia.<br>Treated with intravenous fluids, antibiotics and steroids.<br>The trapped gas can be drawn out via the insertion of a small tube in to the rectum and large intestine.<br>In severe cases, surgery may be required, where the large intestine is removed (colectomy). |
| Rectal or colon cancer | Patients with long term (10 years or more) severe UC have an increased risk of colon or rectal cancer.<br>Symptoms of this type of cancer can be masked by UC as they are similar - blood in the stool, diarrhoea and abdominal pain.<br>Regular gastroenterology reviews and monitoring of symptoms should be provided for long-term UC patients.[6] |
| Osteoporosis and osteomalacia | Osteoporosis and vitamin D deficiency are common in IBD.<br>Major risk factors include older age, steroid use and disease activity.[6] |
| Anaemias | Iron deficiency is common in IBD patients. Regular haemoglobin, ferritin, transferrin saturation and CRP checked should take place.[6]<br>There is also an increased risk of folate or B12 malabsorption in after surgery where the ileum has been involved. |

*Table 2 continued*

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| Obstruction/blockage | Patients undergoing pouch surgery for UC are at high risk for small bowel obstruction due to the combined abdominal and pelvic dissection.<br>Postoperative adhesions, a twisted intestine, herniation of the bowel, or twisting of an ileostomy may result in partial or complete small bowel obstruction.<br>After closure of a temporary ileostomy, obstruction may also occur due to luminal stenosis or adhesions at the closure site.[7] |
| Pouch leakage or bleeding | Soon after surgery, leaks and bleeding may develop from any part of the newly formed pouch, along the suture lines and anastomosis site (ileum to anus).<br>Elderly patients, males, and those on corticosteroids are at greater risk.<br>Pouch ischemia is rare and is characterised by copious dark red blood with clots.[7] |
| Pouchitis. | A longer-term complication, acute or chronic inflammation of the ileal reservoir (pouch).<br>Symptoms include increased stool frequency and urgency, abdominal pain, bloody diarrhoea, fever, faecal incontinence.<br>Treated with antibiotic therapy, e.g. metronidazole and ciprofloxacin.<br>Antidiarrheal drugs to manage stool frequency and urgency. |

Once again, Maria was advised by the stoma care nurse to alter her diet to manage any symptoms. This time she was more anxious about eating, as she was concerned she wouldn't be continent. She opened her bowels for the first time almost two days after the reversal surgery. She passed a type 7 stool,[5] but she was continent and pain free. She was extremely relieved by this. However, for five days after the surgery, Maria struggled to eat anything more than white bread toast and butter, tea with milk and salt and vinegar crisps. She was still anxious to introduce any higher fibre foods, fruits or vegetables. Her stoma care nurse asked her to speak to a fellow patient on the ward who had undergone similar surgery and who was eating well. Maria enjoyed speaking to this patient, an older woman, in her 40s. Hearing the positive experiences this patient had had when introducing foods back in to her diet gave Maria some confidence to try some different foods. She introduced porridge, ham and chicken, potatoes and cooked vegetable such as carrot, parsnip and butternut squash.

She was discharged home after seven days on the ward. Although she needed to open her bowels eight to 12 times per day as she increased her dietary intake, she was able to maintain continence and her stools thickened, often passing type 5 stools.[5] She continued to avoid many of the foods and drinks she hadn't tolerated whilst she had her ileostomy.

After three to four months, Maria's pouch activity had settled and she was opening her bowels six to eight times per day, with continued type 5 stools.[5] Once again she was managing five portions of fruit and vegetables per day; she was also including higher fibre version of breakfast cereals and bread. She considered her diet relatively normal. Her weight had improved again and she was now 56kg, BMI 20.5kg/m$^3$. Three months after her reversal operation, Maria enrolled again at her local sixth form college. She was keen to return to her studies and she felt healthy for the first time in nearly three years. She was able to engage in all of the social and even sporting activities on offer with her peers. She started to play badminton at a local club and she enjoyed swimming two to three times per week. In the two years following her surgeries, Maria remained well for the majority of the time, but she experienced two episodes of pouchitis. See Table 2 for a more information on pouchitis and other complications of UC and pouch surgery. She was successfully treated with courses of antibiotic therapy, including metroniozole and ciprofloxacin.

Ulcerative Colitis, like many chronic diseases, has a major impact on a patient's life. Maria not only experienced significant health problems because of this condition, but her social and mental

health was affected too. In addition, she confronted several dietary challenges, due to physical and psychosocial factors. There is little research available regarding the psychosocial factors of food and the impact that IBD has on quality of life. A study conducted by Hughes et al[8] in 2013, found that in patients with active IBD disease, there were psychosocial issues relating to food and drink. Self-imposed dietary restraints influenced daily eating and drinking, as well as social relationships. Patients with IBD opt to make changes in their diet to control their symptoms and compromises are made when eating with friends and family. Quality of life is often reduced, but little was known about the strategies used by patients to manage these issues. Further research is underway to investigate this, with plans to develop a food-related quality of life questionnaire, which could be used in clinical and research settings. For more information visit - www.kcl.ac.uk/ioppn/depts/psychology/research/ResearchGroupings/healthpsych/research-group/IBD.aspx <accessed 03/03/16>

The management of IBD is only successful through high quality MDT working. The Royal College of Physicians has recently published a report[9] following an audit of IBD services across the UK, looking at areas for improvement in IBS services, but also areas where action has been take or starting to take place. The report includes data from eight regional workshops attended by 258 delegates (including eight dietitians) from 84 trusts and health boards. 125 individual action points were recorded and grouped into 24 themes. The five most common action themes were:

1 patient pathways - biologics, diagnostic, inpatients, pregnancy, standardised care, policy/protocol and shared care
2 IBD nurses
3 IBD Registry/database
4 patient panel/group
5 multidisciplinary team meetings

Dietetic and nutritional support improvement targets were included with some progress being made. This report is the work of The IBD programme team, which was established over 10 years ago. Their aim is to improve the quality and safety of care for people with IBD throughout the UK. Initially, the team audited IBD services to highlight variations across the UK. In recent years, the team has evolved and their work includes a wider range of quality improvement measures and supporting the development of national standards for IBD care. Find more information about the work of the IBD programme at www.rcplondon.ac.uk/ibd.


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