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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 1: Symptoms, diagnosis and early management

Please note that Part 2 of this article can be viewed in the Subscriber Zone online only at www.NHDmag.com

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Case Study

Somewhere in the distance a radio is playing, the DJ chirps about the latest pop hit and happily wishes everyone a good morning. It's 8.25am and 18-year-old Maria is looking down at her bare legs and feet, dangling over the edge of a hospital trolley, feeling a little woozy from the premed. Wearing a hospital gown, she feels a slight chill as the anaesthetist is behind her, pressing an epidural needle into her spine. "There we go, all done. You can lay back down now," he says. Along comes the nurse; she clanks the brake off the trolley with her foot and it starts to move forward. Maria looks up at the white polystyrene tiled ceiling, dotted with bright strip lights, passing overhead like neon clouds; she's calmly wheeled down the corridor to the theatre area where she will undergo major bowel surgery. It has been quite a journey to get here…

At the age of 16, Maria was diagnosed with Ulcerative Colitis (UC) following several weeks of abdominal pain and diarrhoea (Please see Table 1 for a brief outline of UC). Throughout her earlier teenage years, Maria had been an active girl with a good appetite. There was no family history of bowel problems, such as coeliac disease, IBS or inflammatory bowel disease (IBD). At her first GP appointment, following two weeks of abdominal cramps and some diarrhoea, he initially concluded that Maria had had a 'stomach bug' and asked her to return if her symptoms did not improve. Two weeks later, when her symptoms had not improved but had worsened, she returned to her GP who requested blood tests and a stool sample. (Please see Table 2 for common tests for IBD.)

Maria had been experiencing daily abdominal pain, frequently bloody diarrhoea. She was also complaining of fatigue and feeling generally unwell. Her blood tests showed that her FBC and serum ferritin level were low, but not out of range; she was displaying signs of inflammation with raised CRP, ESR and WBC. She was negative for coeliac disease. Her stool sample was negative for bacterial or parasitic infections; however, it was noted that there were traces of blood within the sample. She had also been experiencing loss of appetite and her GP was concerned that she had lost approximately 3.0kg in four to five weeks. Maria explained that this (approximate) 5% weight loss was unintentional. It was due to her feeling nauseous at times and she was now quite anxious about eating; afraid it would cause her increased abdominal discomfort and diarrhoea. Her usual BMI was 20.9km/m^2 (height 1.65cm, weight 57kg). On presentation to this second GP appointment, her weight was 54kg (BMI 19.8km/m^2).

When Maria and her GP discussed her dietary intake, it was apparent that it had reduced by as much as 50% due to her gastrointestinal (GI) symptoms. She was avoiding some foods, such as fresh vegetables and fruits, milk, high fibre cereal and bread. She felt that these foods increased stool frequency and

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abdominal discomfort. Her GP advised lower fibre foods to tolerance, e.g. white bread and pasta with high calorie, protein-containing foods such as cheese, white meat or fish. He also advised her to fortify her food with extra butter, for example, with mashed potatoes or on cooked vegetables, which she was managing at that time. A little and often approach with food was agreed as the best way forward, where high calorie small meals, snacks and drinks would be taken every two to three hours. In light of her test results, Maria was referred to her local hospital's gastroenterology team.

This team reviewed her approximately six weeks afterwards. Her weight was monitored again at this time and she had experienced a further 5% weight loss (BMI 18.7km/m^2 (height 1.65cm, weight 51kg). Prior to this initial appointment, she underwent a repeat set of blood tests, which showed continued raised inflammatory markers and her serum ferritin level, along with her FBC, had worsened. She was diagnosed with iron deficiency anaemia.

Maria attended the hospital two weeks later for a colonoscopy, the outcome of which was a firm diagnosis of UC. Her gastroenterology consultant gave her this diagnosis at a follow-up outpatient appointment approximately four weeks later. He explained that UC was a chronic and ongoing condition with a variety of treatment options. (Please see Table 3 for common treatments used in UC.) By this time, Maria had lost another 2.0kg and her BMI was now 18km/m^2 (height 1.65cm, weight 49kg). She felt tearful and embarrassed that she was experiencing significant urgency to pass very loose stools up to 15 times per day. This had started to occur at night time too, which she felt was affecting her energy levels during the day. She was experiencing broken sleep most nights. Consequently, she had been missing several days per week of her college course due to her lack of energy and GI symptoms. This created further anxiety for Maria as she was falling behind with her academic work. She was also afraid to go along to social events with her peers due to her need to be close to a toilet, and the anxiety she had about discussing her condition. She had similar worries at work. Maria worked part time in a supermarket and she struggled to speak to her colleagues and manager about her health problems.

Her dietary intake diminished further despite her efforts to eat little and often. She was tolerating only plain bland foods, such as mashed potato with tinned tuna, porridge with semi-skimmed milk and sugar, ready salted potato crisps and ham sandwiches made with white bread. She was managing small portions of these foods and she described her appetite as 25% of what it would normally be. She was drinking good amounts of fluids via 800ml of diluted full sugar squash, up to two 'cup-a-soup' type drinks (made up to 250ml each) and two to three cups of tea with milk (made up to 250ml each) per day. She continued to avoid milk as a drink, as she felt it increased her abdominal discomfort and the thought of drinking milky drinks made her feel nauseous. Maria was commenced on an anti-inflammatory medication, Mesalazine, antidiarrhoeals, Loperamide and a course of iron replacement therapy. She was not referred for nutritional advice at this time and the gastroenterology team planned to review her in three months.

At her next review, Maria's weight had remained static at 49kg. She was feeling better in herself and her GI symptoms had eased. She was still experiencing loose stools with urgency up to eight times per day. However, this had decreased significantly at night. Her appetite and dietary intake

Table 1: Overview of ulcerative colitis (adapted from www.crohnsandcolitis.co.uk)[1,2]

Ulcerative Colitis (UC) is one of the two main Inflammatory Bowel Diseases. Approximately one in 420 people (around 146,000 people) in the UK have UC.
It's a chronic long-term condition.
The inner lining of the large intestine and rectum become ulcerated and inflamed causing bleeding and mucus to be secreted.
Inflammation can affect all of the large intestine, known as Pancolitis or Full colitis. It can also affect the rectum only, known as Proctitis.
Affects male and females equally.
Most commonly diagnosed between 15-25 years of age.
Common in white people of European decent.
More common in urban areas and in Northern developed countries.
More common in non-smokers and ex-smokers.
Symptoms
Diarrhoea/Bloody stools
Abdominal pain/discomfort, cramping
Fatigue, sometimes severe
Feeling generally unwell, sometimes feverish
Poor appetite and/or weight loss
Anaemia
Joint, liver, eye and skin conditions can develop as a consequence of UC
Extensive or total colitis (Pancolitis) over many years is associated with an increased risk of rectal or colon cancer

had improved a little, but she was still maintaining a plain bland diet which was similar to that previously reported. As her status was stable, the gastroenterology team planned a further review in three months' time. However, four weeks after her review Maria became unwell with a cold, she felt generally unwell and her appetite reduced. Despite her dietary intake being minimal for several days, she was experiencing loose, bloody stools with urgency almost every hour. She was breathless on exertion, where even having a shower was exhausting. When offered food and drink, she became nauseous and would vomit if she tried to consume them, even water. She was admitted to hospital due to dehydration and severe abdominal pain.

On admission, she was weighed and she had lost 3.0kg. Her BMI was 16.9kg/m^2 (height 1.65cm and weight 46kg). After three days as an inpatient, Maria's GI symptoms improved and she was eating and drinking small amounts. She was discharged on a course of steroids and immunosuppressant medication, Azathioprine. Over the next month, Maria's symptoms improved greatly, she gained 4.0kg and reported that she was eating really well. She had started to eat a wider variety of foods, including lasagna, roast chicken dinners with vegetables and she had reintroduced some fresh fruits, such as banana, melon and satsumas.

At her next review appointment, which was four weeks after her admission, the gastroenterology team advised her to continue with the steroid treatment and Azathioprine for another six weeks, after which the steroid treatment would be gradually reduced, as this was not a long-term option. Maria followed this advice and felt well for the first few reductions in the steroid treatment. However, once the treatment had reached approximately half its full strength, her GI symptoms returned. She was experiencing loose, urgent stools and abdominal discomfort. For the following 18 months, Maria experienced a revolving door of being well, then experiencing severe GI symptoms every few months. Her weight fluctuated between 49-54kg, as she was prescribed several courses

of steroid treatment alongside the Azathioprine. This cycle of remission then 'flare up' meant that Maria missed too much of her college course to complete her examinations and she decided to discontinue her studies. At a similar time, she gave up her part-time job, as she felt too weak to continue.

This had a huge psychological impact on Maria; she felt low in mood and her confidence dwindled. She was angry to have lost control of her health and her life to UC. She was often tearful and dreaded waking up in the morning, as she knew she would feel fatigued and frustrated. Eating and drinking became 'autopilot' functions, where she would eat the same foods most days, as it was easy to cope with. She did not want to eat anything else, food held little enjoyment for Maria at that time.

Just after her 18th birthday, Maria attended her usual three-to-four-monthly gastroenterology review. She was feeling unwell, she was experiencing a 'flare up', where she had a constant dull ache in her abdomen, she was passing loose bloody stools every hour and she was tolerating only small amounts of a plain bland diet. According to the Truelove and Witts' severity index, she was experiencing severe UC.[5] Tired of being unwell and fatigued, Maria became very emotional during her discussions with the gastroenterology consultant. It was at this time that he raised the option of surgical intervention. This was a challenge for Maria to accept, as continuing with her current treatment was unlikely to be a successful path, yet surgical intervention was terrifying. What was worse? Continuing with her current situation or having surgery to remove her large intestine and fashion a new pouch from her small intestine: a restorative proctocolectomy with ileoanal pouch (see Table 3)? It was a major decision to make at the age of 18, but Maria felt that she had no choice. Surgery was the best option and two months later, she was booked in for the procedure. Weighing 45kg (BMI 16.3kg/m^2), Maria was malnourished, but she was not referred for dietetic intervention at this time.

Keep reading! Part 2 of this case study is available online in the Subscriber Zone at www.nhdmag.com and includes Maria's post-surgical experiences, diet with an ileostomy and, finally, her ileoanal pouch.

Table 2: Common bloods tests used in Inflammatory Bowel Disease (adapted from www.labtestsonline.org.uk)[3]

Blood tests	
White blood cell count as part of a full blood count (anaemia screening included) ESR (erythrocyte sedimentation rate) CRP (C-reactive protein) Coeliac disease screening	
Stool tests: Stools sample examinations to exclude other causes of diarrhoea and inflammation	
Stool culture	To detect bacterial infection.
Ova and parasite examination	May cause diarrhoea and temporary bowel inflammation.
Clostridium difficile screening	To detect toxin created by bacterial infection, which may follow antibiotic therapy.
White blood cell count (WBC)	To detect the presence of WBC, indicative of infection or inflammation.
Faecal calprotectin	A protein found in cells associated with inflammation. The concentration of calprotectin in faeces correlates with the level of bowel inflammation present. The concentration of faecal calprotectin therefore tends to be increased in IBD (a disease characterised by inflammation), but not in IBS (Irritable bowel syndrome, a disease which is not characterised by inflammation). A negative faecal calprotectin result supports the diagnosis of IBS. National Institute for Health and Care Excellence (NICE)[4] recommend that faecal calprotectin testing might be useful to support clinicians in differentiating IBD from IBS. Monitoring calprotectin may also be useful to help monitor IBD and detect a flare-up.

Table 2 continued

Non-laboratory tests – for diagnosing and monitoring IBD. Used to look for characteristic changes in the structure and tissues of the GI tract	
Barium meal and follow through	Barium contrast dye is ingested by the patient followed by abdominal x-rays to examine the small intestine.
Sigmoidoscopy	An examination the last two feet of the colon using an endoscopy. Biopsies may be taken.
Colonoscopy	An examination of the entire colon; using an endoscopy. Biopsies may be taken.
Biopsy	Small tissue samples taken from the large intestine to be examined for inflammation and abnormal cell structure changes.
MRI and CT scans.[2,9]	May be used to look at the location and extent of inflammation Ultrasound may be used in some cases, e.g. pregnancy and IBD.

Table 3: Treatment options in UC (adapted from Crohn's and Colitis UK - Ulcerative Colitis: Your guide[2])

Anti-inflammatory drugs - to reduce inflammation	
Aminosalicylates or 5-ASAs	Mesalazine (brand names include Asacol, Ipocol, Octasa, Pentasa, and Salofalk), sulphasalazine (Salazopyrin), olsalazine (Dipentum), balsalazide (Colazide)
Corticosteroids, often just called steroids	Prednisolone, hydrocortisone, budesonide, beclometasone dipropionate
Immunosuppressants	Azathioprine, mercaptopurine or 6MP (Purinethol), methotrexate, mycophenolate mofetil, tacrolimus and ciclosporin
Biological drugs	Infliximab and vedolizumab
Symptomatic drugs - to control and reduce common GI symptoms	
Antidiarrhoeals	Codeine phosphate, diphenoxylate (Lomotil) and Loperamide (Imodium, Arret)
Laxatives	Movicol and Lactulose
Bulking agents	Fybogel
Analgesics	Paracetamol and aspirin
Probiotic therapy	
VSL#3	A probiotic containing eight different strains of bacterial (450 billion per sachet).[6] There is evidence to suggest it may be helpful in preventing pouchitis[7,9] (inflammation of an ileo-anal pouch - further information below). However, there is limited evidence for the use of probiotics in maintaining remission in people with UC.[8,9]
Surgical options	
Proctocolectomy with permanent ileostomy	Removal of the whole large intestine, rectum and anal canal. The end of the lower small intestine is brought onto the wall of the abdomen to form a permanent ileostomy. This form of surgery is irreversible.
Restorative proctocolectomy with ileoanal pouch	Often called pouch surgery, or IPAA (Ileal Pouch-Anal Anastomosis). The preferred form of surgery for UC. Requires two operations, but may be completed in a single stage or in three stages. In the first operation the whole large intestine and the rectum are removed, the anus is left in situ. A pouch is constructed using the end of the ileum, which is joined to the anus. A temporary ileostomy is formed by bringing a looped section of the small intestine onto the wall of the abdomen. This allows the newly formed pouch anastomosis to heal. This takes several months. To close the temporary ileostomy a second operation will take place once the pouch is healed. In very rare cases, the whole procedure is done in one stage, without the ileostomy.

Table 3 continued

Colectomy with ileorectal anastomosis	Removal of the whole large intestine. The ileum is joined to the rectum. It avoids the need for a stoma. Can be useful for people who may not cope with an ileostomy or who are unsuitable for pouch surgery. This operation is only suitable if there is little or no inflammation in the rectum or if there is no long-term risk of developing cancer in the rectum.
Colectomy with ileostomy (subtotal)	Often performed in an emergency. Removal of the whole large intestine but leaves the rectum in situ. This allows for the possibility of pouch surgery in the future. The end of the ileum is brought out onto the abdomen wall to form an ileostomy. The upper end of the rectum is either closed or brought out to the surface to form another stoma. This additional stoma (sometimes called a mucous fistula) may be needed because the rectum may still produce mucus for a while. After recovering from this surgery, patents can then decide whether to opt for pouch surgery or a permanent ileostomy.

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