Inflammatory bowel disease nursing

#### Note

Health and social care practice and knowledge are constantly changing and developing as new research and treatments, changes in procedures, drugs and equipment become available.

The authors, editor and publishers have, as far as is possible, taken care to confirm that the information complies with the latest standards of practice and legislation.

## Inflammatory bowel disease nursing

edited by

Kathy Whayman, Julie Duncan and Marian O'Connor



Quay Books Division, MA Healthcare Ltd, St Jude's Church, Dulwich Road, London SE24 0PB

British Library Cataloguing-in-Publication Data A catalogue record is available for this book

© MA Healthcare Limited 2011

ISBN-10: 1 85642 404 9 ISBN-13: 978 1 85642 404 2

All rights reserved. No part of this publication may be reproduced, stored in a retrieval system or transmitted in any form or by any means, electronic, mechanical, photocopying, recording or otherwise, without prior permission from the publishers

Printed by CLE, Huntingdon, Cambridgeshire

V

Foreword Preface About the editors Contributors	vii ix xi xiii
Part 1 The nature of inflammatory bowel disease	
Chapter I Pathophysiology Louise Langmead	3
Chapter 2 Epidemiology Clive Onnie	29
Chapter 3 Clinical features Ailsa L. Hart	47
Part 2 Clinical management	
Chapter 4	

Investigating inflammatory bowel disease61Siew C. Ng and Nisha Patel

Chapter 5 Nursing assessment Julie Duncan	81
Chapter 6 Medical management of inflammatory bowel disease in the adult general setting Kirstin M. Taylor and Peter M. Irving	95
Chapter 7 Management of the patient with more complex IBD Jeremy Sanderson and Melissa Smith	117
Chapter 8 Dietary considerations in IBD Miranda Lomer	139
Chapter 9 Surgical management Sue Clark	159
<b>Chapter 10</b> <b>Ileoanal pouch care</b> Zarah L. Perry-Woodford and Simon D. McLaughlin	179
Chapter II Caring for stomas and fistulae Jennie Burch	201
Chapter 12 Intestinal failure Jeremy Nightingale and Hannah Middleton	223
Chapter 13 Fertility, pregnancy and IBD Julie Duncan and Lisa Younge	241

Chapter 14 Care of children and adolescents with IBD John M. E. Fell	259
Chapter 15 Managing the transition from paediatric to adult care Kay Greveson and Vikki Garrick	281
Chapter 16 Psychosocial aspects of inflammatory bowel disease Sonya Chelvanayagam and Anton Emmanuel	295
Chapter 17 Living with inflammatory bowel disease – a patient's experience Sneha Wadhwani and Marian O'Connor	315
Chapter 18 <b>Living with IBD – the role of patient support organisations</b> <i>Helen Terry</i>	325
Chapter 19 Supporting and educating patients Kathy Whayman	333
Part 3 Advancing practice	
Chapter 20 Organisation of IBD care Richard Driscoll	359
Chapter 21 Developing the role of the Clinical Nurse Specialist in IBD Cath Stansfield, Julie Duncan, Marian O'Connor and Kathy Whayman	375

Chapter 22	
Setting up specialist nursing services	397
Marian O'Connor	
Chapter 23	
Getting research into practice	415
Christine Norton	
Chapter 24	
A vision of the future: celebrating the increasing sphere of	
influence	425
Isobel Mason	
Index	437

## Foreword

Rozlynn Prescott

I was diagnosed with ulcerative colitis back in March 2008. Unfortunately, I became so ill I had to take six months off work. My weight plummeted from ten stone to six and a half. Before I got UC, I was confident, ambitious, energetic and sociable, and I loved sport. Within weeks of getting IBD, this all changed. Months later, and thankfully in remission, I discovered I was pregnant. After being so ill, it was a miracle it happened and I soon forgot about the past and looked to the future. Pregnancy was bliss and I felt good again until the eighth month, when I felt the symptoms return. Our beautiful, healthy daughter, Ava Grace Prescott, was born on 26 May 2009. When I returned home with my little girl I became extremely ill within days. I tried breastfeeding but found this impossible, as I spent most of my time, both day and night, on the toilet. My husband finally convinced me to return to hospital. I was admitted immediately and put under the care of my consultant gastroenterologist and his team. I was told that if my bowel was not removed, I would die. This was just two weeks after giving birth. I couldn't get my head around it all, and when I was informed that I would have to have a stoma bag my heart sank. Despite having a wonderful baby girl, I cried and told them I would rather die. The gastroenterologists were very caring and took time to explain to me that if I had my large colon removed, it would mean no more colitis, that a bag was not for life, and that I could have it reversed. It took a while, but they convinced me and I did, for the first time, see light at the end of the tunnel.

Once the decision had been taken, I was booked in for emergency surgery. This was a success, and for two months I was honoured to have a brilliant team help me recover. Since then I've had my ileoanal pouch formed and reversal. It was a really tough time and I ask myself how I got through it all. But I did and it was thanks to the amazing, dedicated medical team I was lucky enough to have care for me. These included the stoma care and IBD specialist nurses, the anaesthetist, surgeons, gastroenterologists, pain team, physiotherapists and dietitians. The ward nurses' care and attention kept me going and they did everything to help so that

#### Foreword

Х

I could spend as much time as possible with my beautiful baby when I began to recover. It was all hands on deck and I never had a moment's peace – and that of course was a good thing! Importantly, my family formed their own team and rallied together to help in any way they could. They all were equally fantastic and I couldn't have got through any of this without them. I realised then how important, supportive and loving a family can be, and that I was one of the lucky ones. They dropped everything and were there for me, my husband and my little girl 24/7.

My experience highlights the importance of the multidisciplinary team in caring for patients with IBD and their loved ones. The role that nurses play in providing holistic, high quality care is so valuable. Nurses need to have access to educational material which can then be translated directly into patient care. This is where a book such as *Inflammatory Bowel Disease Nursing* comes in: to help future nurses and members of the team develop their understanding of IBD and, most importantly, communicate that knowledge to their patients.

Kathy, Julie and Marian have brought together an impressive group of professionals and patients – all experts in their field – to create a comprehensive, practical and relevant text. Any nurse working in IBD practice will find this book an invaluable asset to support their clinical care and learning ventures.

## Preface

One of the motivations behind the development of this book was the surprising discovery by one of the editors (Julie), that there was no existing inflammatory bowel disease nursing textbook to support and inform her in her new role as an IBD nurse. At the same time it had been identified by Kathy and Marian that the academic IBD modules they were running at the Burdett Institute of GI Nursing would benefit from a dedicated supporting text.

There are many excellent tomes written by doctors for doctors. These texts form an important part of the education of nurses caring for people with IBD. They can, however, lack the practical applicability that nurses need to help them provide high quality, holistic, evidence-based care. Hence, *Inflammatory Bowel Disease Nursing* has been written around real-life (anonymised) case studies with the role of the nurse in mind. We have been privileged to have expert authors contribute to this book, who have shared their extensive experience, and without whom this book would have not been possible.

The book has been divided into three parts. The first is entitled The Nature of IBD. This part includes chapters on the pathophysiology, epidemiology and clinical features of IBD, providing a sound basis for the rest of the book.

The second part is entitled Clinical Management, a comprehensive part which draws on both evidence-based practice and the extensive clinical expertise of the authors. There is a unique patient translation summary at the end of each clinical chapter to aid the nurse explain the key points of the chapter to their patients in easily understood language. Within this section, there is an important chapter outlining one contributor's personal experience of being diagnosed with IBD and their subsequent adaptation to living with the condition. This gives insight into the patient's perspective and the effects of the disease and its treatment on lifestyle, as well as highlighting the importance of a multidisciplinary approach to care.

Finally, the third section is entitled Advancing Practice. This section is aimed predominantly at established IBD nurses and those who are interested in working in a specialist role. Chapters are written with the purpose of providing practical and strategic support for nurses and other professionals in setting up and developing services and specialist skills.

#### Preface

This is not a text by nurses for nurses, but rather reflects the multidisciplinary nature of IBD teams and of IBD care. This is achieved with excellent contributions from gastroenterologists, surgeons, nurses, dietitians, support groups and, very importantly, patients who are at the centre of IBD management. Although specifically aimed at nurses we strongly feel that the book will be useful to all healthcare professionals caring for people with IBD.

> Kathy Whayman, Julie Duncan, Marian O'Connor December 2010

#### Acknowledgements

We'd like to thank all the contributors for sharing their expertise so willingly, and Quay Books for their guidance. Our colleagues have been a huge source of support, advice and encouragement; Claire Taylor and Marlene Sastrillo deserve particular mention. Special thanks to our families for their enthusiasm for the project and belief in us, particularly Ian Gray, and Kate and Andrew Duncan. Finally, big thanks and love to Matt, Jimi and James for their patience, ongoing support, encouragement, and tolerance of all the disrupted evenings, weekends and holidays!

Kathy, Julie and Marian December 2010

## About the editors

Kathy Whayman MSc PGDip (Healthcare Ed) DipN RN qualified in 1991 and moved to St Mark's Hospital to specialise in gastrointestinal care. She took up post as a Macmillan Colorectal Nurse specialist in 2001, whilst completing her MSc in 2003. Kathy then became a Lecturer for The Burdett Institute of Gastrointestinal Nursing, in partnership with King's College London and St Mark's Hospital, helping to set up and deliver education programmes for GI nursing. This work involved developing clinical modules on IBD care, and included the first Masters-level module in IBD Advanced Nursing Practice. Research interests include gastrointestinal patient information and education, most specifically in inflammatory bowel disease (IBD) and colorectal cancer nursing service development. Kathy coedited *The Oxford Handbook of Gastrointestinal Nursing* and has presented to UK and European nursing forums on education for nurses, self-management, informational care in IBD and colorectal cancer nursing practice. Kathy has now taken a career break following the birth of her second child, and looks forward to contributing to gastrointestinal nursing care again in the near future.

Julie Duncan MSc RGN currently works as a Clinical Nurse Specialist in Inflammatory Bowel Disease at Guy's and St Thomas' NHS Foundation Trust, London. She developed her interest in GI/colorectal nursing during her training at Edinburgh Royal Infirmary. She worked at St Mark's Hospital from 1995 and in 2000 joined the internationally renowned team of Biofeedback Specialist Nurses, becoming the Lead Nurse for the service in 2002. She was active in the teaching and research commitments of both the clinical service and The Burdett Institute of Gastrointestinal Nursing, including being clinical lead for the bowel continence and biofeedback modules. She has extensive experience in developing and leading specialist nursing services at St Mark's Hospital, Royal Marsden Hospital, London and now Guy's and St Thomas'. Julie has presented widely nationally and internationally. She retains part-time lecturing responsibilities as clinical lead for the MSc IBD module with the Burdett Institute.

**Marian O'Connor** RGN joined the team at St. Mark's Hospital in 2005 as an IBD Clinical Nurse Specialist, and took over as the Lead Nurse for this service

#### About the editors

in 2008. Marian is currently the clinical lead for the IBD Degree (BSc) module at the Burdett Institute of Gastrointestinal Nursing, providing lectures and tutorial support. On a European Nursing level, Marian is currently the Networking Officer for NECCO (Nurses European Colitis & Crohn's Organisation) and the chair in waiting for NECCO, due to commence from February 2011.

Marian has presented at various meetings and conferences at national, European and international level on IBD Nursing. She also peer reviews articles for publication for the *British Journal of Nursing* and *Gastrointestinal Nursing* (GIN), and her recent publications include two chapters for the *Oxford Handbook of Gastrointestinal Nursing*. Marian has completed the BSc and MSc IBD Nursing Modules, and is planning to commence her Masters in GI Nursing in January 2011.

**Jennie Burch** MSc, BSc, RN is an enhanced recovery nurse facilitator at St Mark's Hospital, Harrow, UK. Jennie has varied experience in colorectal nursing including almost eight years as a stoma specialist nurse, working with people with inflammatory bowel disease, high-output stomas, enterocutaneous fistulae and colorectal cancer. She has written several articles and a edited a book entitled *Stoma Care*.

**Sonya Chelvanayagam** MSc, RN, PgDip (Learning & Teaching) is a Senior Lecturer in Mental Health at the University of Hertfordshire. She is a registered mental health nurse and adult nurse who has worked in a variety of settings with people who experience either physical or mental illnesses or a combination of physical symptoms and mental health problems. Sonya works currently on a part-time basis, both as a Nursing Research Fellow at the Burdett Institute for Gastrointestinal Nursing and as a Senior Lecturer in Mental Health at the University of Hertfordshire.

**Sue Clark** MD FRCS (Gen Surg) is Consultant Colorectal Surgeon at St Mark's Hospital, Harrow, and Honorary Senior Lecturer in Surgery at Imperial College, London. She has a clinical and research interests in inherited colorectal cancers and inflammatory bowel disease. In particular, she performs high volumes of ileoanal pouch surgery, and is active in studying and managing pouch dysfunction.

**Richard Driscoll** worked as a Social Worker in London before becoming Administrator and Patients' Advocate to the Home Dialysis Programme of St Bartholomew's Hospital. He then worked with Vicky Clement-Jones in establishing CancerBACKUP as a leading provider of cancer information before moving to his current role as Chief Executive for Crohn's and Colitis UK. During his 19 years in post he has developed the charity to be the leading provider of information and support to patients as well as campaigning for better services and raising funds for research. He also chaired the working group that produced the UK IBD Service Standards in 2009.

Anton Emmanuel BSc, MD, FRCP obtained his medical degree from London University. He is a Senior Lecturer in Neuro-Gastroenterology at University College London and Consultant Gastroenterologist at University College Hospital, the National Hospital for Neurology and Neurosurgery (Queen Square) and the Royal National Orthopaedic Hospital (Stanmore). He currently supervises eight postgraduate research fellows undertaking higher degrees. He is the Chairman of the Neurogastroenterology section of the British Society of Gastroenterology and Medical Director of Core, the largest UK gastrointestinal charity.

**John Fell** is head of Paediatric Gastroenterology at Chelsea and Westminster Hospital London, running the paediatric inflammatory bowel disease clinical services for West London, and an Honorary Senior Lecturer with Imperial College. His research has focused on mucosal inflammation in paediatric gastrointestinal disorders, and in particular the effects of nutritional therapy in Crohn's disease.

**Vikki Garrick** BSc RGN RSCN qualified as RGN in 1991 then as RSCN in 1993. Vikki worked in the Royal Hospital for Sick Children in Glasgow as a staff nurse in the burns unit for seven years in total as a junior then senior staff nurse. Vikki became a Paediatric Tissue Viability Nurse Specialist in 2000, which is where the crossover with Inflammatory Bowel Disease (IBD) occurred. She has set up and rolled out the Paediatric IBD Nursing service in Glasgow over the course of the last four years and managed a caseload of approximately 300 children and families, successfully implementing the first programme in the UK for the home administration of methotrexate for paediatric patients with IBD. She is also a founder member and now chair of the first national paediatric IBD nurse forum as part of the RCN special interest group. This group has been instrumental in raising awareness of paediatric issues and the need for family-centred care in paediatric IBD.

**Kay Greveson** qualified as a nurse in 2001 and has a background working on a medical Gastroenterology ward and endoscopy. She has been working as an IBD specialist nurse for the past four years, initially at Sheffield Teaching hospitals, and for the past two years at the Royal Free Hospital, London. She is a qualified independent nurse prescriber and is currently working towards her Masters degree. She has particular research interests in transitional care in IBD and screening for latent tuberculosis prior to anti-TNF therapy. She has published on these topics in a variety of medical and nursing journals and has presented both nationally and internationally. She has been involved in various national projects, including the NICE appraisals for anti-tnf in Crohn's and ulcerative colitis, and more recently a RCN nurse advisor for the Biologics registry.

Ailsa Hart BA (Hons) BMBCh, MRCP, PhD is Honorary Consultant Gastroenterologist at St Mark's Hospital and Senior Clinical Lecturer for Imperial College.

**Peter Irving** is a Consultant Gastroenterologist at Guy's and St Thomas' Hospitals in London specialising in inflammatory bowel disease. He is widely published in the field and is regularly invited to talk on the management of IBD. He has edited two IBD textbooks and co-authored an information book for patients. He is on the editorial boards of Crohn's and Colitis UK and the journal *Inflammatory Bowel Diseases*.

**Louise Langmead** MBBS MD FRCP is a Consultant Gastroenterologist at The Royal London Hospital, specialising in Inflammatory Bowel Disease with a research interest in complementary therapy for IBD.

**Miranda Lomer** qualified as a dietitian in 1990. In 2002 she completed a PhD on diet and Crohn's disease. In 2007, Dr Lomer was appointed as a Consultant Dietitian in Gastroenterology at Guy's and St Thomas' Hospitals, London with a joint academic position at King's College London. Her research interests are diet and the nutritional management of inflammatory bowel disease and functional gut disorders. She has been the chair of the Gastroenterology Specialist Group of the British Dietetic Association (BDA) from 2006–2010.

**Isobel Mason** RGN, MSc, MCGI is currently employed at the Royal Free Hospital as a Nurse Consultant in Gastroenterology, leading and developing other nurses within the speciality and making strategic decisions about improving and advancing nursing practice. Her clinical role includes a busy inflammatory bowel disease nursing service alongside two other clinical nurse specialists, and clinics for patients with dyspepsia, coeliac disease, iron deficiency anaemia and family history of colorectal cancer. Isobel chaired the Royal College of Nursing Gastroenterology & Stoma Care Forum until January 2009, representing the group in the development of the Quality Care Standards for IBD care.

Simon McLaughlin is a Consultant Gastroenterologist at the Royal Bournemouth Hospital and Visiting Research Fellow in the Nutritional Sciences Division, King's College London. Simon's area of clinical interest is inflammatory bowel disease. His MD thesis was on the pathogenesis and management of pouchitis and he has published widely in this area.

**Hannah Middleton** completed the Diploma HE in Nursing Studies at King's College London. Following this training, she was appointed as a staff nurse within

the neurology department of King's College Hospital. She occupied this post for just over five years, at which point she was successful in application for a fixed term nutrition nurse position at University College London Hospitals. Due to the temporary nature of this role she progressed to Inflammatory Bowel Disease nurse and has been in this specialty since 2008. Hannah has been fortunate to have gained experience in the nursing of the patient with both intestinal failure and inflammatory bowel disease. She has had the opportunity to work within specialist teams which have offered tremendous support and knowledge. Recently, Hannah has thoroughly enjoyed completing her first Master's module in inflammatory bowel disease advanced practice, and hopes to continue with her Master's programme at King's College London.

**Siew C. Ng** MBBS PhD MRCP is a Gastroenterologist at the Prince of Wales Hospital, Chinese University of Hong Kong. She qualified from St Bartholomew's and the Royal London School of Medicine and Dentistry in 2000, trained in gastroenterology in London from 2000 to 2004, and was awarded a PhD in the modulation of immune cells with bacteria therapy in intestinal inflammation by Imperial College London in 2009. She has published extensively and received several research prizes. Her research interests include inflammatory bowel disease and intestinal infections.

Jeremy Nightingale MD FRCP has been a Consultant Gastroenterologist at St Mark's Hospital specialising in intestinal failure and inflammatory bowel disease since April 2006. For 10 years previously he was a Consultant Gastroenterologist and General Physician at Leicester Royal Infirmary, where he set up and established a nutrition support team. He originally trained at St Mark's Hospital under the guidance of Professor J. E. Lennard-Jones. He was awarded the Sir David Cuthbertson Medal by the Nutrition Society in 1993 for his work on the problems of a short bowel. He has edited a bestselling textbook entitled Intestinal Failure. He is the chairman of the BAPEN (British Association of Parenteral and Enteral Nutrition) Regional Representatives and chairman of the independent charity The Nightingale Trust for Nutritional Support (1109586). He is the vice chairman of the Royal College of Physicians Nutrition Committee and is a member of the British Society of Gastroenterology Small Bowel and Nutrition Committee. Jeremy has published and lectured widely, and has represented the BSG on NICE clinical guideline development on Nutritional Support for Adults. He is currently the editor of the British Journal of Home Healthcare. He became the treasurer to the Coloproctology Section of the RSM in 2009. Jeremy is also Co-chair of the Intestinal Failure Unit in St Mark's Hospital and an Honorary Senior Lecturer with Imperial College.

**Christine Norton** RN MA PhD is Nurse Consultant (Bowel Control) St Mark's Hospital Harrow and Professor of Clinical Nursing and Innovation at Bucks New University and Imperial College Healthcare NHS Trust London. Christine combines clinical practice with research and teaching, leading a team of nurses and physiotherapists who treat patients with functional bowel disorders. She chaired the 2007 NICE guideline on faecal incontinence and publishes and lectures widely.

**Clive Onnie** BSc(Hons) MSc PhD MRCP is a Consultant Gastroenterologist at the Whittington Hospital, London, and Honorary Senior Lecturer, Royal Free and University College Medical School. He undertook his research in the Genetics of Inflammatory Bowel Disease, and acts as the Medical Adviser to the North London Chapter of Crohn's and Colitis UK.

**Nisha Patel** qualified from the Royal Free and University College Hospital Medical School in 2004. She underwent postgraduate training at Hammersmith, St Mary's and Charing Cross Hospitals. She was appointed to the North West Thames Gastroenterology and Internal Medicine registrar rotation in 2008 and is currently at the West Middlesex Hospital. She has published and presented widely at international and national gastroenterology conferences and has an interest in inflammatory bowel disease.

Zarah Perry-Woodford RN DipN is currently pursuing her MSc in gastrointestinal nursing. Zarah has served in the Royal Air Force as a military nurse on a general/colorectal ward. In 2002, she joined St Mark's Hospital and worked as a Senior Staff nurse on Frederick Salmon ward and then as a Clinical Nurse Specialist in stoma care, where she managed patients with stomas, ileoanal pouches, enterocutaneous fistulae and those with intestinal failure. Since 2005 Zarah has worked as the Clinical Nurse Specialist in Pouch Care providing expert care to patients with ileoanal pouches both pre- and post-operation. She also runs an outpatient nurse-led clinic and email and telephone helpline. She has researched and published in a variety of medical and nursing journals and enjoys contributing to undergraduate and postgraduate education.

Jeremy Sanderson is a Consultant Gastroenterologist at Guy's and St. Thomas' Hospital and Senior Clinical Research Fellow in the Nutritional Sciences Division, King's College London. He qualified in 1984 at Charing Cross Hospital and undertook his Post-Graduate training in London and Australia. He was appointed Consultant at Guy's and St. Thomas' Hospital in 1995. His major clinical interest is in the optimal management of Crohn's disease and ulcerative colitis but other specialist areas include colonoscopy, oral manifestations of IBD and irritable

bowel syndrome. His research interests include the genetics, microbiology and immunology of Crohn's disease and individualised medicine through pharmacogenetics. He is a regular lecturer on IBD and has published widely in this field. He was secretary of the British Society of Gastroenterology from 2001 to 2005.

**Melissa Smith** BSc (Hons), MB, ChB, MA (Medical Ethics), PGCert Med Ed, MRCP is a Gastroenterology Specialist Registrar at Guy's and St Thomas' NHS Foundation Trust, completing research into the optimisation of immunomodulation in IBD.

**Cath Stansfield** is a IBD Nurse Specialist at Salford Royal Hospitals NHS Trust, and the current chair of the RCN IBD Nurses Network. She has a wide experience of IBD and IBD nursing spanning over 12 years as a specialist nurse, and additional experience in medical gastroenterology and intestinal failure. Her current interests include service redesign for patients with complex Crohn's disease. Cath has a number of publications in national and international nursing journals, along with presentations at both national and international level.

**Kirstin Taylor** MBBS MRCP is a research registrar in IBD genetics at Guy's and St Thomas' Hospitals NHS Foundation Trust & King's College London.

Helen Terry BA (Hons), CQSW is Director of Information and Support at Crohn's and Colitis UK. She is a member of the Association's Senior Management Team. and her responsibilities include managing the Association's information and support services, including the production of Crohn's and Colitis UK's publications. She is editor-in-chief of *NACC News*, the Association's quarterly newsletter, and she takes the staff lead in Crohn's and Colitis UK's programmes of research and campaigning on issues related to living with IBD. Helen is also a member of the Information Standard Executive Council (Crohn's and Colitis UK is the working title for the National Association for Colitis and Crohn's Disease.)

**Sneha Wadhwani** was diagnosed with IBD aged 14 years while at secondary school. With the care she received and her determination she managed to progress through education and schooling as normal with no loss of time due to the illness. She studied at University of Leicester Medical School and qualified as a doctor in 2002. Sneha went on to train in General Practice under the esteemed Riverside Vocational Training Scheme in Chelsea, London, and qualified as a GP in 2006, attaining diplomas in paediatrics, obstetrics, and gynaecology and family planning along the way. She ended the year on a high by marrying her husband. In 2007 she became a partner in a large practice in Harpenden, Hertfordshire, and in

2010 completed the Postgraduate Certificate in Medical Education and became a GP trainer. This was shortly followed in 2010 by the birth of her daughter. Her treatment has continued throughout and is ongoing. IBD has been a huge part of her life, and has helped to define who she is both as a person and also as a doctor. Though times have often been hard and some things have been a struggle, it has given her more than it has taken away.

**Lisa Younge** RGN, BSc (Hons) works as the IBD nurse specialist at Bart's and the London NHS Trust, having previously worked at the Whittington Hospital and St Mark's Hospital in similar roles. Her focus is on patient support, and her service includes nurse-led clinics and running the telephone helpline service for IBD patients in the trust, working in close collaboration with the MDT to ensure continuity and accessibility for patients. She is the current chair of the European Nursing Network for IBD – NECCO – and has published on various aspects of both therapies and the nursing role within IBD.

 PART I

# The nature of inflammatory bowel disease

1

#### CHAPTER I

## Pathophysiology

Louise Langmead

#### Introduction

Inflammatory bowel disease (IBD) is exactly what it sounds like: a disease of the bowel in which it becomes inflamed. Specifically, IBD describes an idiopathic, chronic, relapsing and remitting inflammatory disorder of the gastrointestinal tract.

Two main conditions are included under the heading of IBD. These are ulcerative colitis and Crohn's disease. There are also a number of other rarer conditions which may be classified as IBD (Figure 1.1). There is much overlap between the different conditions both in the way they affect people, the bowel pathology, and their association with other conditions. There is also overlap among possible factors which probably contribute to the development of the different types of IBD, such as genes.



Figure 1.1 Classifications of IBD.

#### The normal gut

In order to understand the pathophysiology of IBD, it is worth revising the anatomy and physiology of the healthy gut. For patients, terminology in the human gut can

#### Inflammatory bowel disease nursing

be confusing because there is often more than one word used for the same part. A simple explanation can make it is easier to appreciate how disease of different parts can cause quite different problems and symptoms.

#### Anatomy

The human gut (Figure 1.2) is a long hollow tube which starts at the mouth. Next is the oesophagus, then the stomach, the small intestine, the large intestine and finally the anus. The small intestine is made up of the duodenum, jejunum and ileum. The large intestine is made up of the colon and rectum which attaches to the anus. The gut is attached to various other organs along its course, including the liver and pancreas, which are important in its digestive function.



Figure 1.2 The human gut.

Pathophysiology

#### **Physiology**

The overall functions of the gut are to get food into the body, to convert it into useful fuel to be delivered to the organs, and to dispose of the waste products.

#### Digestion

The gut, the salivary glands, pancreas, liver and gall bladder are all organs of digestion. Food is processed in the stomach by a combination of chemical hydrolysis by gastric acid, digestion by proteolytic enzymes and salivary amylase, and mechanical breakdown due to gastric motility. Further digestion occurs in the upper small bowel, where pancreatic juices containing proteases, lipase and amylase are released into the duodenum under the influence of the hormones cholecystokinin and secretin, among others. Fat is emulsified in the presence of bile which is also released through the common bile duct into the duodenum. The combined fluid volume from gastric, pancreatic, biliary and small bowel secretion, in response to eating a meal, is up to 7 litres. The major function of the small intestine is to absorb fluid, ions and nutrients as the products of digestion (sugars, amino acids and fats) back across the gut mucosa into the capillaries. In order to achieve this, the small intestinal lumen has an enormous surface area, thanks to the presence of crypts and villi along its length as well as microvilli on each epithelial cell (Figure 1.3). Nutrients are carried in the blood to the liver, to be stored or utilised as energy. What remains in the small intestine at the end of this process passes into the colon through the ileocaecal valve. At this point, the bowel content is liquid. However, as it passes along the colon, most of the water is reabsorbed through the colonic wall into the mesenteric vessels. By the time the stool reaches the rectum it is therefore solid, not liquid. Passage of fluid and food along the GI tract is facilitated by peristalsis, which is a coordinated contraction of the muscle layers of the gut to cause propulsion of a bolus along the tube. The act of defecation is controlled by a complex process including sensation of rectal distension and conscious and subconscious control of the anal sphincters.

#### Malfunction

When any part of the gut becomes diseased, processes can go wrong in a variety of ways, causing illness. This may result in symptoms in the affected organ (for example a stomach ulcer causing pain) or it may cause failure of energy production (for example weight loss due to malabsorption). Symptoms of IBD will be discussed in more detail in Chapter 3.



Figure 1.3 The human gut in cross-section.

#### The mucosal immune system

The lamina propria of the gut mucosa houses a large number of immune cells which form the mucosal immune system. This is in constant flux with the systemic immune system, with recruitment of cells to the gut from the blood under complex control mechanisms. The intestinal mucosa is continuously exposed to a wide variety of luminal antigens originating from the diet and resident micro-organisms. To avoid an acute inflammatory response to such antigen exposure, mucosal immune cells behave differently from their systemic counterparts. There is a socalled immunological tolerance which results from down regulation of lymphocyte and macrophage activation by antigen exposure. Regulation of the mucosal response to antigens is determined in part by a balance of pro-inflammatory and anti-inflammatory molecules, particularly cytokines which are in turn, regulated by nuclear transcription factors.

CD 4 T lymphocytes play an important role in initiating immune responses. They provide help in activating other immune cells among a variety of other effector functions. When naïve CD4 cells are activated by antigenic stimulation, they expand and differentiate into different subsets with individual characteristics. These are Th1 and Th2 and more recently recognised Th17 subsets (Bettelli et