



Putting **patients**
at the **HEART**
of everything we do



**London North West
University Healthcare**
NHS Trust



**Adult Inflammatory Bowel Disease (IBD) Services
at
London North West University Healthcare NHS Trust**

Introduction

We are aware that living with Inflammatory Bowel Disease (IBD) is not easy. Our aim is to support you to live with this condition. We pride ourselves on not just treating the disease but the person living with it, so we designed our service to reflect your needs. This information booklet describes the various services we offer. These are covered by different team members ranging from doctors, surgeons, nurses, pharmacist, dietitian, research coordinators and administrators. The booklet gives contact details for the healthcare professionals that may be involved in your care. We do hope you find it useful.

Useful numbers

Hospital switchboards

Central Middlesex Hospital	020 8965 5733
Ealing Hospital	020 8967 5000
Northwick Park & St Mark's Hospitals	020 8864 3232 020 8235 4000

Trust Website	www.lnwh.nhs.uk
St Mark's Hospital website	www.stmarkshospital.nhs.uk

IBD Nursing Team

Advice Line (voicemail)	020 8235 4155
IBD Nurse secretary	020 8235 4026
IBD Day Unit	020 8869 5488
Fax	020 8869 5487

Outpatients department

Access Centre for appointments at:	
Central Middlesex Hospital,	
Ealing Hospital & Northwick Park	020 8235 4200
St Mark's Hospital	020 8235 4051

Endoscopy department

Central Middlesex Hospital	020 8963 8828
Ealing Hospital	020 8967 5617
St Mark's Hospital	020 8235 4130

Secretary numbers

Central Middlesex Hospital

Gastroenterologists

Dr Amar Sharif	020 8453 2364
Dr David Sherman	020 8453 2364

Ealing Hospital

Gastroenterologists

Professor Jayantha Arnold	020 8967 5513
Dr Charlotte Bearcroft	020 8967 5513
Dr Arvind Sangwaiya	020 8967 5375

Dr Arabinda Pal	020 8967 5375
Dr Sohail Shariq	020 8967 5513

Surgeons

Mr Tushar Agarwal	020 8967 5611
Mr Ashish Sinha	020 8967 5875

Northwick Park and St Mark's Hospitals

Gastroenterologists

Dr Ayesha Akbar	020 8869 5808
Dr Naila Arebi	020 8235 4124
Dr Suzanne Donnelly	020 8235 4089
Dr Simon Gabe	020 8235 4089
Professor Ailsa Hart	020 8869 5808
Dr Adam Haycock	020 8869 2628
Dr Adam Humphries	020 8869 5277
Dr Meron Jacyna	020 8869 3997
Dr Nik Kamperidis	020 8869 3058
Dr Andrew Latchford	020 8235 4091
Dr Ravi Misra	020 8869 5808
Dr Mani Naghibi	020 8869 4084
Dr Maxton Pitcher	020 8869 2630
Professor Brian Saunders	020 8235 4225
Dr Amar Sharif	020 8869 3058
Dr Siwan Thomas-Gibson	020 8235 4091
Dr Ana Wilson	020 8869 5277

Colorectal Surgeons

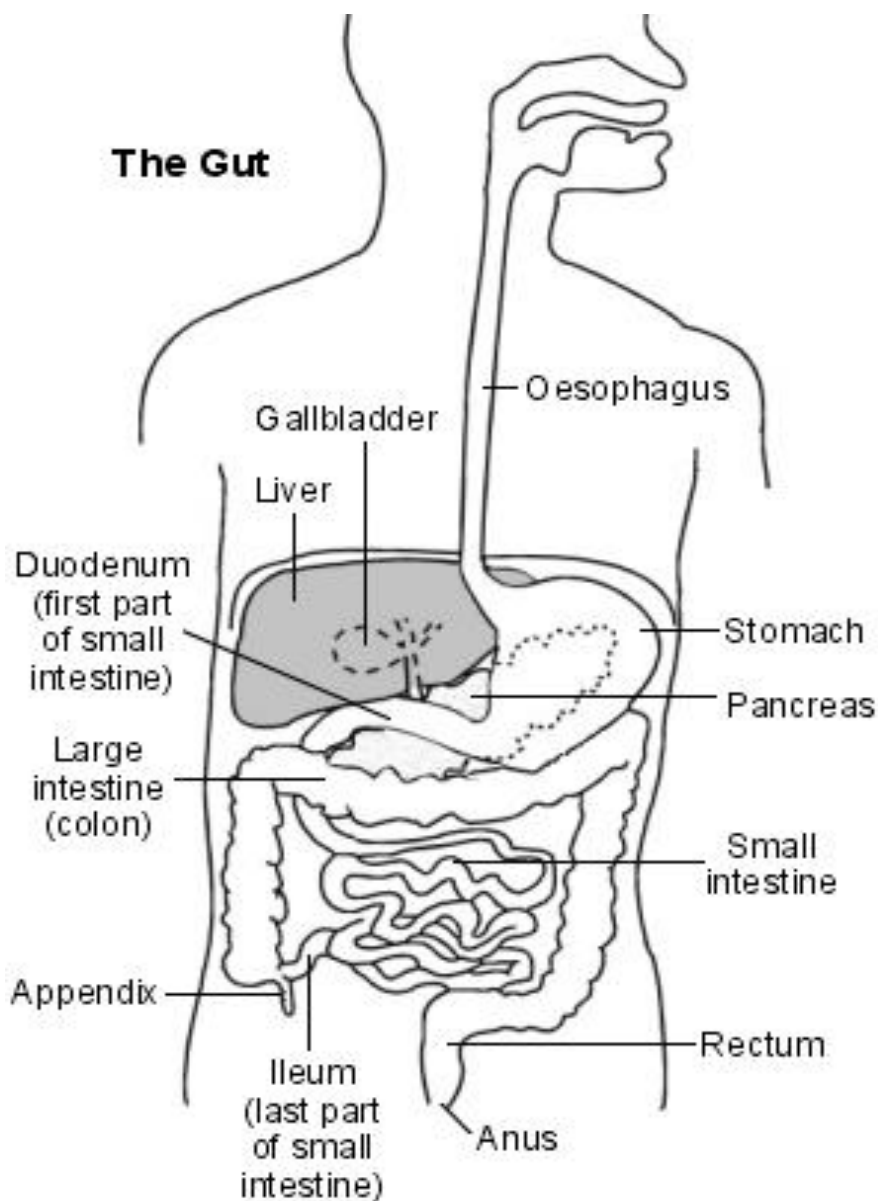
Mr Antony Antoniou	020 8235 4177
Professor Sue Clark	020 8235 4018
Professor Omar Faiz	020 8235 4077
Mr Ian Jenkins	020 8235 4177
Mr Peter McDonald	020 8869 5196
Mr Akash Mehta	020 8235 4177
Mr Danilo Miskovic	020 8235 4018
Mr Phil Tozer	020 8235 4195
Miss Carolyn Vaizey	020 8235 4020
Mr Janindra Warusavitarne	020 8235 4168

My IBD ID

This page should help you to understand a bit more about your IBD. The diagram may help you to visualise your disease and its extent, so ask your Dr/Nurse/Surgeon to identify the areas where you have IBD.

I have Affecting
my.....

diagnosed on



Our services

Our service encompasses all aspects of IBD Care: medical, nursing and surgical management, psychological and nutritional support, research and education. The transition service is led by the paediatrics department.

Northwick Park and St Marks Hospitals

Acute in-patient gastroenterology is delivered at Northwick Hospital, supported by the specialist services available at St. Mark's Hospital. Outpatient and endoscopic services are provided within St Mark's Hospital.

St Mark's Hospital is the only hospital in the world to specialise entirely in intestinal and colorectal medicine and is the UK's leading national and international referral centre for intestinal diseases, seeing both locally and nationally referred patients. As well as clinical services, St Mark's has many research interests and a very active programme of teaching and education. The Wolfson Unit for Endoscopy at St Mark's Hospital is the only unit in the UK internationally recognised as a world centre of excellence by the World Endoscopy Organisation and one of only 15 worldwide providing a wide range of diagnostic and therapeutic endoscopic procedures.

Central Middlesex Hospital

Gastroenterology outpatient IBD clinics also run at Central Middlesex Hospital and endoscopic services are provided in the ACAD centre there.

Ealing Hospital

Gastroenterology outpatient clinics and endoscopy services are provided by two full-time consultants and two part-time consultants with a team junior medical support with a matron leading the inpatient care for this speciality.

Paediatrics

There is a paediatric IBD service based at Northwick Park Hospital which currently consists of one paediatric gastroenterologist and one paediatric IBD Nurse. They work closely with the paediatric IBD team at Chelsea and Westminster Hospital. A transition and dedicated young adult clinics are jointly held once a month in St. Mark's Hospital with a dedicated adult gastroenterologist to support seamless transfer into adult services.

The Inflammatory Bowel Disease staff:

Gastroenterologists

We have a large number of gastroenterologists (doctors who specialise in conditions affecting the bowel) who have a team of specialist registrars working alongside them and will help manage your IBD from a medical perspective. We manage both locally and nationally referred patients, providing outpatient and inpatient treatment for medical patients. We offer several joint clinics (clinics with different members of the multidisciplinary team present i.e. surgeon and gastroenterologist) to reduce the number of appointments that you have to attend and also maximise the professional input into your care. Your gastroenterologist will inform you if you require further input from other members of the multidisciplinary team and if you are being booked into a different clinic.

As well as managing your IBD the gastroenterologists perform a full range of endoscopic techniques including diagnostic and therapeutic examination of the upper and lower gastrointestinal tract. These are undertaken in all our endoscopy units.

Surgeons

We have a highly experienced team of surgeons who are experts in performing operations using keyhole surgery techniques, as well as open surgery. The surgical team consists of consultants and junior surgeons (RSOs) who will manage your IBD from a surgical aspect if necessary.

We understand that contemplating surgery can be daunting. When surgery is first discussed you will be advised to have a consultation with one of our highly experienced surgeons or a joint appointment with your gastroenterologist and prospective surgeon present. The purpose of this appointment is to ensure that you have a clear understanding of the surgical options that may be available to you. This is also an ideal time to have any questions you may have answered.

IBD Nurses

We have a highly skilled team of IBD Clinical Nurse Specialists (IBD CNS) and IBD nurses who should be your first point of contact should you require any advice regarding your disease. More specifically, they can provide support, advice and

information on your inflammatory bowel condition and medication, including biological medicines management.

The advice line (020 8235 4155) is run by the IBD CNSs and we encourage you to leave a message should you have any query relating to your disease, and particularly if you are becoming unwell. The IBD nurse specialists can assess and advise you over the phone and if appropriate make an appointment for you to be seen by a doctor or nurse in the outpatient department. You can access the advice line during weekdays, but it is important to remember that if you are very unwell you should seek alternative advice from your GP or local accident and emergency department, as at busy times it may be more than 24hrs before your call is returned. You may also wish to contact the Crohn's and Colitis UK helpline to support you with your medical problems (see page 15).

The IBD CNSs also run nurse-led clinics in the outpatient department, alongside their medical colleagues, which can be particularly helpful to those who have had a recent diagnosis of IBD. Other patients who are seen in the IBD CNSs clinic include patients who may be starting new treatments and need more information or subsequent monitoring and patients who have stable IBD for routine checks and monitoring. The IBD CNSs also run telephone clinics for more stable patients to prevent them needing to attend the outpatient clinic when they are well. These clinics are available across all hospital sites by pre-booked appointments.

Many medications used for the treatment for IBD require regular blood tests, and if you are having difficulty organising this with your GP, your clinic doctor can refer you into our immunosuppression monitoring clinic. You may contact us on the advice line to discuss this.

IBD day unit nurses

The IBD day unit is run by our IBD nurses and is located on level 4 of St Mark's Hospital, catering for IBD patients from all three hospital sites. Biological treatments such as Infliximab, Methotrexate, Vedolizumab, Golimumab and Ustekinumab are administered on the IBD day unit. The IBD nurses are dedicated to running the unit and providing these treatments at planned appointments only.

As it is a very busy unit, we highly encourage you to keep their appointments. If you are unable to attend, please contact the administrator. It may not always be possible to rearrange an appointment to your preferred time.

The IBD day unit administrator can be contacted on 020 8869 5488 between 8.30am and 4.30pm Monday to Friday.

In 2019, St Marks and Trust executive agreed to transfer all stable patients on infusions to a new mobile unit in partnership with McKesson and Lloyds pharmacy to meet the rising demand for these drugs and accommodate patients needing to start new treatments. All care, consultant oversight remains under the care of St Marks, the only difference is that the infusions are delivered off-site in a bespoke mobile unit. The mobile unit is much like the mobile breast screening units or MRI units that you may have seen.

Dietitians

There are dietetic teams available on all three hospital sites along with an IBD specific dietitian at St Mark's Hospital. The dietitians are available (by referral) to offer support, guidance and information regarding nutritional aspects of your disease. Your doctor or nurse may discuss dietetic support with you and will make a referral to the dietetic team if they think it is appropriate.

IBD Pharmacist

Each site (Ealing, Central Middlesex, Northwick Park and St. Mark's Hospitals) has their own pharmacy teams but are all overseen by the chief pharmacist based at Northwick Park Hospital. The St Mark's Hospital pharmacy team supply medications to the IBD day unit as well as providing prescriptions for patients on homecare. They are based separately from the pharmacy dispensary but work with the dispensary team to ensure seamless care. The St Mark's Hospital team have a dedicated IBD pharmacist who works closely with the IBD nurses to assist in the monitoring of medications which reduce the immune system, such as azathioprine or mercaptopurine, through telephone clinics as well as clinics to assess patients who are being considered to start treatment with biological medicines, as part of the multi-disciplinary team.

Nutrition nurses

Occasionally patients with IBD may require a period of nutritional support where a tube is placed either directly into the gastrointestinal tract (enteral nutrition) or a catheter inserted into the bloodstream (parenteral nutrition). There is a nutrition nursing service available for training patients on the care of these devices and troubleshooting any problems that may arise from their use. The nutrition nursing team is headed by a Nurse Consultant in Nutrition, supported by Nutrition Clinical Nurse Specialists. You will be given their contact details if you need to access this service.

Stoma care

The stoma and pouch CNS team see patients in hospital before surgery and offer support and guidance throughout the process. The team also provides on-going support to patients with a stoma or ileo-anal pouch. At Central Middlesex Hospital, the ward nursing team are able to access the team for advice on managing inpatients through the stoma care department. If appropriate, a clinic appointment can be arranged in the out-patient department to see the stoma nurses.

For patients who live in the local area (London Borough of Harrow) there are several out-patient clinics. For patients who live outside the local area, you should be referred by your surgical team to a local stoma care service which will be able to offer follow up support closer to home.

The service can be accessed from 8am to 5pm, Monday to Friday 0800-1700, on the following numbers (voicemail facilities available).

020 8235 4110 (all stoma care issues)

020 8235 4126 (all ileo-anal pouch care issues)

Psychological Medicine Unit (PMU)

The St. Mark's Hospital PMU is headed by a Consultant Psychiatrist and several Psychologists.

The psychological medicine unit is ideally placed to offer psychological assessment and support to patients with gastrointestinal conditions. Following an initial assessment, you may be offered on-going therapy within the unit or

locally (closer to home). It can sometimes be difficult to cope with aspects of living with a long-term condition or illness, and psychological support can be made available. If you feel that this service would be of benefit, please discuss a referral with your medical team.

Inflammatory Bowel Disease services

Outpatient clinics

The clinics are by booked appointments only. Each gastroenterologist has a team of specialist junior doctors (registrars) who work alongside them. It may not always be possible for you to see your gastroenterologist personally, and you may see one of the registrars during your appointment.

The aim of an outpatient appointment is to review your current symptoms and if appropriate undergo a physical examination. It also gives you the opportunity to discuss any concerns you may have. When you first arrive, please expect to be weighed by the outpatient nursing staff and they are also available to assist you whilst you are in the department. If you require a blood test following your appointment, these are also carried out in the department.

Blood test room opening times:

St Mark's Hospital	Monday to Friday	9am to 5pm
Central Middlesex Hospital	Monday to Wednesday	9.30am to 4pm
	Thursday	9.30am to 4pm
	Friday	9am to 1pm
Ealing Hospital	Monday to Friday	8am to 4.30pm

It is helpful for us to have as many contact details for you as possible, and for you to ensure that these are up to date. If any of your personal details have changed, please inform the receptionist at the clinic.

Further appointments

In order to ensure that your appointment is effective, any investigations planned previously should, if possible, be completed prior to your next visit. If you find that this is not the case, please notify the outpatient department so that they can alter your follow-up appointment.

Appointments with the IBD team are available both in clinic and over the telephone. Follow-up appointments are decided following your consultation and arranged by the outpatient department administration team. An appointment letter will be posted out to your home address. If you are unable to attend your appointment, please phone the outpatients department to rearrange it.

Your GP is likely to be closely involved in your care at all times. After each clinic appointment in the hospital, your GP will be informed of any changes to your care plan (and medications) by a letter. A copy of this correspondence will be sent to you.

Please be aware that you are entitled to seek a second opinion either within the Trust or elsewhere if you wish to do so. Please discuss with your current consultant or GP if you would like to explore this possibility further.

Prescriptions

Some initial prescriptions need to be issued from the hospital pharmacy (based within Northwick Park, Central Middlesex and Ealing Hospitals). You will be advised by the pharmacist about your medications when you collect them. Please be aware that it is normal for you to be given a limited supply from the hospital pharmacy and your GP will then be asked to prescribe any further prescriptions. It might be worth considering a pre-payment certificate which can significantly reduce the cost of your regular prescriptions – speak with your local pharmacist for more information about this.

Pharmacy dispensary details:

Northwick Park and St Marks Hospital	020 8869 2200
Monday to Friday, 9am to 5.45pm, Saturday 9.30am to 12.30pm, Sundays/Bank holidays 9.30am to 12noon	
Central Middlesex Hospital	020 8453 2552
Monday to Friday 9am to 5pm, Saturday/Bank Holidays 9.30 to 1pm	
Ealing Hospital	020 8967 5532
Monday 9.30am to 5.30pm, Tuesday to Friday 9am to 5.30pm	

If you have any questions regarding the medications you have been prescribed, please contact Medicines Information Enquiries on 020 8869 2762 (Monday to Friday 9am to 5pm) to speak with a pharmacist.

Research and clinical trials

St. Mark's Hospital strives for clinical excellence, innovative research and top-quality education and teaching.

Research is an important part of any clinical area helping us to understand the effectiveness of existing treatments and to discover new ones. Our vision is to create a future free from the fear of bowel disease through research, education and dissemination of clinical excellence. Our dedicated research team is willing to come and talk to patients, families and visitors about active research studies within IBD and give them detailed information about it.

We have an extensive portfolio of studies in IBD addressing factors such as genetics or the gut microbiota (bugs that live within us) related to the cause of the disease, the effectiveness of new treatments and new ways to assess and monitor the disease such as with special scans and blood tests.

If you would like any further information about Inflammatory Bowel Disease (IBD) research or if you are interested in participating in research studies, please contact the Research Team at LNWH-tr.IBDResearch@nhs.net or call at 020 8869 506.

Endoscopy

The Wolfson Unit for Endoscopy was established in 1996 as a National centre for endoscopy and is based at St Mark's Hospital. It has been recognised internationally as a World Centre of Excellence, by the World Endoscopy Organisation and is the only centre in the UK to be recognised in this way. Examinations such as gastroscopies, colonoscopies are performed here. The endoscopy departments at Central Middlesex and Ealing Hospitals are slightly smaller units but offer a similar service.

Radiology

The imaging departments at St Mark's, Northwick Park, Ealing and Central Middlesex Hospitals offer a comprehensive range of x-rays and scans. The specialist radiologists are pioneering new techniques such as virtual colonoscopy, CT/MRI of the small bowel and also imaging of complex inflammatory bowel disease.

Feedback

We are regularly auditing our service and value your feedback and you may be approached to complete a satisfaction survey. So that we can continue to improve your experience, please do help us by telling us what you think about the services we provide. You can also provide feedback at www.iwantgreatcare.com.

Inflammatory Bowel Disease networking, information and support

St Mark's IBD Patient panel

The IBD Patient Panel meets every two months to discuss topics of care within the hospital. This forum is for patients who use the services in the hospital to provide the team with feedback and suggestions for improvements.

The IBD Patient Panel has made a huge contribution to developing the IBD service at St. Mark's hospital including hosting the IBD Open Day. Further information can be found on the website www.stmarkshospital.nhs.uk/about/ibd-patient-panel/

If you would like to contribute to the IBD Patient Panel by either attending meetings or by highlighting a particular area you would like to see the panel address, please don't hesitate to get in touch with the IBD Nurses at LNWH-tr.ibdnurse@nhs.net

Education opportunity

The Royal College of Nursing (RCN) London IBD nurses in London have developed a programme of education, supported by IBD Nurses and Doctors, for people living with IBD. The IBD Patient Education Programme will cover a wide

range of topics such as 'What is IBD' and 'Pregnancy and Fertility'. For more information visit www.crohnsandcolitis.org.uk/pep for session information and dates.

Travel advice

For comprehensive, practical and reliable information about travelling with IBD there is a great resource developed by an IBD CNS at www.ibdpassport.com that we would recommend.

Crohn's and Colitis UK

Crohn's and Colitis UK have developed a fantastic resource that offers a wide variety of support and information for patients with Crohn's Disease or Ulcerative colitis. They are also at the forefront of developing standards of care and support a variety of research projects to improve care for IBD patients and their families. Visit their website at www.crohnsandcolitis.org.uk or call the helpline: 0300 222 5700 from 9am to 5pm on Monday to Friday (except English bank holidays). Helpline calls may be recorded or monitored for training and evaluation purposes. Crohn's & Colitis UK's policy on confidentiality is in accordance with the Data Protection Act (1998). Alternatively you may wish to email: info@crohnsandcolitis.org.uk or have a live chat with other people with IBD at www.crohnsandcolitis.org.uk/livechat.

Crohn's in Childhood Research Association (CICRA)

CICRA are a charity dedicated to improving the care for children with inflammatory bowel disease. They are a smaller organisation but offer similar services to Crohn's and Colitis UK. Their website can be found at www.cicra.org with a dedicated Helpline on 0208 949 6209 or email at support@cicra.org

forCrohns

forCrohns mission is to fund research that helps those with the condition today and contributes to finding a cure for Crohn's disease in the future, whilst making more people in the UK aware of the disease and its symptoms. Their website www.forcrohns.org has details about how to become involved and also explains the support they can offer people with Crohn's disease.

Inside out (stoma support group)

Inside out hold coffee mornings every two weeks at St Mark's hospital and is an opportunity for people with stomas to have a chat with other stoma patients and learn from their experiences. They invite manufacturers to come and keep you up to date on the latest bags etc. and also have someone to talk about subjects that are of interest to stoma patients. Access their website at www.issog.org.uk or email them at info@iossg.org.uk.

IA (The Ileostomy and Internal pouch support group)

IA are a national organisation supporting people of all ages who have a stoma or internal pouch. They can be contacted on Freephone 0800 0184 724 or email them at info@iasupport.org. Their comprehensive website with all things relating to stomas and internal pouches can be found at www.iasupport.org.

Colostomy UK

Colostomy UK offer support and information to ostomates of all ages who have a colostomy. Their website can be found at www.colostomyuk.org. They offer a 24hour helpline on Freephone 0800 328 4257 and you can email them at info@colostomyuk.org.

Guts UK

Guts UK is the only charity in the UK that is committed to fighting all conditions and diseases that affect the gut, liver and pancreas. They do this by funding research, providing expert information for people affected, their families and their carers through their website info@gutscharity.org.uk and promote awareness and discussion about digestive health. You can email them at info@gutscharity.org.uk or telephone 020 7486 0341.

RADAR key (for disabled toilets)

RADAR are focused on helping disabled people with a basic right - to find the toilets which they need and to then reliably gain access. Their website www.radarkey.org contains information on how to order keys and identifies some toilet finding apps.

London North West University Hospital facilities and shops:

There are a wide variety of shops and facilities in our hospitals.

St Mark's Hospital (level 3 by outpatients)

- Friends of St Mark's Tea Bar Monday to Friday 8am - 4pm
Run by volunteers who serve snacks and hot and cold drinks

Northwick Park Hospital (level 4 along the main corridor)

- Adam's Apple Fruit Stall Monday to Friday 6am to 4pm
- Bliss Dry Cleaners Monday to Friday 9am to 5pm
Full dry-cleaning service, laundry service, garment repair, mobile repairs and top ups
- COSTA Coffee Monday to Sunday 8am to 8pm
- League of Friends Gift Shop Monday to Saturday 9am to 5pm
- Marks & Spencer Monday to Friday 7am to 9 pm
Saturday 7am to 8.30 pm
Sunday, 8am to 8.30 pm
- The Cutting Room (Hairdressers) Monday to Friday 9am to 6pm
Haircuts, manicures and pedicures available in the salon and at bedside
Tel: 020 8869 3954
- The Wellspring Cafeteria Monday to Sunday 6.30am to 8pm
Offering a wide variety of hot and cold meals including a Subway counter
- WHSmith Convenience Store Monday to Sunday 7am to 8pm

Ealing Hospital

- Friends Cafe (Level 2, Out-Patients) run by volunteers serving a range of snacks and hot and cold beverages
Monday to Friday 8.30am to 5pm
Saturday & Sunday 12pm to 2pm
- 24 (Level 1, basement) Serves hot and cold meals and snacks
Monday to Friday 7am to 3pm

- Costa Coffee (level 2, main entrance)
Monday to Friday 7am to 8pm
Saturday & Sunday 8am to 6.30pm
- WHSmith (Level 2, main reception)
Monday to Friday 7.30am to 8pm
Saturday 9am to 8pm
Sunday 10am to 7pm

Central Middlesex Hospital

- WHSmith (Main reception)
Monday to Sunday 7am to 8pm
- WHSmith Café (Main reception)
Monday to Sunday 7am to 6pm

Cash points

Cash points are located at the main reception of all our hospitals - please check before use as fees may apply

WiFi

A guest and public WiFi service is available at all three sites, provided by WiFiSpark and offers 24-hour free internet access, or a paid for premium service.

Search for NHS WiFi using your phone or tablet: For support or enquiries please contact 0344 848 9555

Toilets

We have a number of toilet facilities on all sites. These are clearly signposted within the hospital areas.

General Trust information

Patient Advice and Liaison Service (PALS)

PALS is a confidential service for people who would like information, help or advice about the services provided by any of our hospitals. Please call 020 8869 5118 between 9.30am and 4.30pm or e-mail LNWH-tr.PALS@nhs.net.

Please note that this service does not provide clinical advice so please contact the relevant department directly to discuss any concerns or queries about your upcoming test, examination or operation.

If you would like this information in an easy to read format, large print, braille, different format or language, please contact the PALS team on 020 8869 5118 or email lnwh-tr.PALS@nhs.net. We will do our best to meet your needs.

Inflammatory Bowel Disease Service

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