National Hospital for Neurology and Neurosurgery

Adult Inherited Metabolic Disease Services
Charles Dent Metabolic Unit
If you need a large print, audio, braille, easy read, age-friendly or translated copy of this document, please contact us on 02034484778. We will try our best to meet your needs.

Contents

1. When will I be transferred to the adolescent and adult services? 4
2. Where are the outpatient clinics located? 4
3. Who works at the Charles Dent Metabolic Unit? 4
4. What happens if I am seeing other specialists at Great Ormond Street Hospital? 7
5. Who will I contact in the event of a medical emergency? 8
6. How often will I be seen in the outpatient clinic? 8
7. All my prescriptions come from the pharmacy at Great Ormond Street Hospital, what will happen when I transfer to adult services? 8
8. I have been receiving enzyme infusions at home, what will happen when I transfer to adult services? 9
9. How to contact us 9
10. Patient support groups and organisations 10
11. Notes 11
12. Where to find us 12
This booklet has been written especially for teenagers and their families to help them prepare for their move from the paediatric (children’s) services at Great Ormond Street Hospital to the adolescent and adult services at the Charles Dent Metabolic Unit.

We know that moving hospital can be a little daunting as there are a lot of new people to meet but we hope to make this process as smooth as possible.

Both metabolic services work closely together and we meet once a week for a teaching and research meeting. We also share some of our laboratory testing facilities.

The Charles Dent Metabolic Unit is one of the largest and longest established services for adults with inherited metabolic diseases in the world. It was established at University College Hospital by Professor Charles Dent after the Second World War.

In 2000, the service was moved to its current location. Currently over 1400 patients attend the Unit which is also an NHS England Specialised Services centre for patients with lysosomal storage disorders.
1 When will I be transferred to the adolescent and adult services?

This move may happen at different ages but generally between the age of 16 and 18 years. The paediatric team will discuss with you when would be the most appropriate time. Your paediatric team will refer you to the adolescent services and provide them with all your relevant medical data. If you have a brother or sister close in age to you attending the paediatric clinic we will try and transfer both of you together. Before you transfer to adult services the team from the Charles Dent Metabolic Unit will also come and meet with you at your last appointment in Great Ormond Street Hospital.

2 Where are the outpatient clinics located?

Adults (16 years and over) are seen in the Basil Samuel Outpatient Department at the National Hospital for Neurology and Neurosurgery (Queen Square).

Some patients (who are very stable on treatment) might also be able to be seen by video consultation for follow-up – to reduce the need to travel to hospital frequently. If this is something that you would like to arrange then ask us about this when you meet us in clinic for the first time.

3 Who works at the Charles Dent Metabolic Unit?

Dr Robin Lachmann and Dr Elaine Murphy are the two medical consultants. You will see one of these doctors when you come to clinic. The doctors provide a 24 hour, 365 days a year on-call emergency service by telephone and can be reached on 020 3448 4778 Monday to Friday from 9am to 5pm. Outside these hours call the UCL Hospital switchboard (0845 155 5000
or 020 34567 890) and ask for the adult inherited metabolic disease consultant on call. Please make sure you keep these numbers in a handy place.

On occasion other doctors undergoing specialist training in inherited metabolic diseases may also attend the outpatient clinic. Other members of the team include clinical nurse specialists, research nurses, dietitians, a dietetic assistant, secretaries, a research assistant and a clinical psychologist.

The **nurses** are involved in the running of clinical trials, coordinating enzyme infusions, starch loads and other investigations in our day ward and attend the lysosomal storage disease clinic.

The **dietitians** work very closely with women with phenylketonuria (PKU) during pregnancy and keep in regular phone contact with all patients as needed. If you are on a prescribed metabolic diet one of the dietitians will see you at every clinic visit.

Our **dietetic assistant** runs our metabolic kitchen and teaches patients how to measure protein exchanges and incorporate their daily protein allowance into a meal plan correctly and effectively. The dietetic assistant also arranges sampling of low protein dietary foods and supplements and cooking with these products.

The **secretaries** are responsible for sending out all correspondence and arranging outpatient and inpatient appointments. They also arrange follow-up appointments for the children of mothers with PKU treated during pregnancy. If you need to change or cancel your appointment please call or
email them so that we can give your appointment to someone else.

The **clinical psychologist** performs neuropsychological (thinking skills) testing and full psychological assessment for patients. The psychologist can also advise on access to therapies if required. We also provide neuropsychological follow-up for all children born to mothers with inherited metabolic disorders, particularly PKU.

---

The Maggie Lilburn Metabolic Kitchen (located on the second floor of the Royal London Hospital for Integrated Medicine) is used to provide education for patients receiving specialist metabolic dietary therapy.
What happens if I am seeing other specialists at Great Ormond Street Hospital?

Either your current paediatric specialist or our doctors will refer you to the appropriate adult specialist as needed. We have links with physiotherapy, urology, ophthalmology, epilepsy, neurology, haematology and gastroenterology specialists at both the National Hospital for Neurology and Neurosurgery and the main UCL Hospital on Euston Road.

Some of the teams that we work most closely with include:

**Cardiology**
Professor Perry Elliott and team
The Bart’s Heart Centre, St Bartholomew’s Hospital

**Neurosurgery**
Mr Adrian Casey and Mr Parag Sayal
National Hospital for Neurology and Neurosurgery

**Gynaecology**
Ms Melanie Davies
University College London Hospital, Euston Road

**Epilepsy**
Dr Sanjeev Rajakulendran
National Hospital for Neurology and Neurosurgery
5 Who will I contact in the event of a medical emergency?

When you see us for the first time in clinic, if needed we will give you an up-to-date ‘emergency regimen’ or ‘sick day rules’ sheet. This will give you and your local GP/hospital doctor instructions on what to do if you become unwell. For some disorders, copies of these emergency regimens are also available on www.BIMDG.org.uk. One of the metabolic doctors will always be available by telephone and can be contacted via the UCL Hospital switchboard outside office hours, call 0845 155 5000 / 020 3456 7890 and ask for the adult inherited metabolic disease consultant on-call. However, please be aware there is no accident and emergency department at the National Hospital for Neurology and Neurosurgery.

6 How often will I be seen in the outpatient clinic?

This will vary depending on medical needs, but in general most patients on a metabolic diet are seen every six months.

7 All my prescriptions come from the pharmacy at Great Ormond Street Hospital – what will happen when I transfer to adult services?

We have a specialist metabolic pharmacy, located on the ground floor of the hospital (Telephone 0203 448 3160), which will continue to supply all specialist medicines.

In general adult patients will need to pay prescription charges – but some individuals are exempt and others can reduce the cost by purchasing a prepayment certificate. Further information is available at https://www.nhsbsa.nhs.uk/help-nhs-prescription-costs/free-nhs-prescriptions
8 I have been receiving enzyme infusions at home – what will happen when I transfer to adult services?

You can continue to receive infusions at home – our specialist nurses will co-ordinate this.

9 How to contact us

Charles Dent Metabolic Unit
The National Hospital for Neurology and Neurosurgery
Internal Mailbox 92
Queen Square
London WC1N 3BG

Email: uclh.metabolic.enquiries@nhs.net
Direct line: 020 3448 4778
Fax: 020 7209 2146
Secretaries and doctors: 020 3448 4778
Nurses: 020 3448 3606
020 3448 3272
020 3448 3607
Dietitians: 020 3448 3604
020 3448 3605
020 3448 4332
Dietetic assistant: 020 3448 3602
Clinical psychologist 020 3448 3406

After hours emergency: 0845 155 5000 or 020 3456 7890 (UCLH switchboard)

The nurses and dieticians are also happy to keep in contact with you by email and we can give you their email addresses when we see you in the outpatient clinic.
10 Patient support groups and organisation

Metabolic Support UK (formerly Climb) – for all IMDs
08452412173; www.metabolicsupportuk.org

Genetic alliance UK
0207 831 0883; www.geneticalliance.org.uk

The National Society for Phenylketonuria
0303 040 1090; www.nspku.org

Galactosemia Support Group
0121 378 5143; www.galactosemia.org

ALD Life
0207 701 2628; www.aldlife.org

The Alkoptonuria Society
0122 332 2897; www.akusociety.org

Fabry Support and Information Group
www.fabry.org

Gauchers Association
0145 354 9231; www.gaucher.org.uk
Association for Glycogen Storage Disease
0300 123 2790; www.agsd.org.uk

Society for Mucopolysaccharide Diseases
03453899901; www.mpssociety.org.uk

Niemann-Pick UK
0191 415 0693; www.npuk.org

TMAU support website
www.tmau.org.uk

The Lysosomal Storage Disorders (LSD) Patient Collaborative Group
www.lsdcollaborative.org

Space for notes and questions
Where to find us

Publication date: January 2010
Date last reviewed: June 2020
Date next review due: June 2022
Leaflet code: NHNN /SHB/CDMU/AIMDS/
© University College London Hospitals NHS Foundation Trust 2009