



# A guide to services for people with sickle cell and thalassaemia

Whittington Health has a long history of providing holistic care for children and adults with sickle cell and thalassaemia. In conjunction with University College London Hospitals (UCLH) we treat the largest number of people with thalassaemia in the UK and advice patients from all over the globe.

We embrace the principle of managing our patients within a multidisciplinary team comprising hospital and community professionals. We work closely with voluntary organisations including the Sickle Cell Society and the United Kingdom Thalassaemia Society so we can provide holistic, patient centred care to all our patients.

## Acute services -The Whittington Hospital

### Accident and Emergency

The A&E at the Whittington is open 24 hours a day 7 days a week. Patients can present here and will be triaged by the staff. We have tried to make sure that sickle cell disease patients are prioritised and that they receive painkillers within the NICE guidelines. We give regular teaching to the A&E staff. The A&E staffs are also aware to discuss any problems with the haematologist on call.

The children with sickle cell disease and thalassaemia are issued with a paediatric passport that gives them a direct access to the paediatric ward, children ambulatory unit and Roses Day care unit and are only seen in A&E if brought by an ambulance.

### Ambulatory Care

Adults and children can be assessed on the adult and paediatric ambulatory care units. All children with haemoglobinopathy should have an Emergency Card (EC) that entitles the child to direct access to the paediatric team, bypassing the Accident and Emergency Department (A&E). This unit is opened between 8- 8:30pm. (Monday to Sunday)

Adults who present to A&E between 0900 and 1630 Monday to Friday can, if they meet certain criteria, be transferred to the Ambulatory Care Unit. We have found that for simple painful crisis that patients get seen quicker and get their painkillers faster if they are seen on this unit. This means that some patients can avoid an admission. However if you are too unwell for the Ambulatory Care Unit (e.g. low oxygen saturations) then you will be kept in A&E where there is more monitoring and support available.



## Outpatient services -The Whittington Hospital

### Transfusion service

Children requiring phlebotomy, blood transfusions or exchange transfusions are cared for on Roses day care unit situated within the Paediatric department on level 4. The unit is open from 7.30am to 7.30pm Monday to Friday.

Adults are cared for on the Thalassaemia unit situated next to Mercers ward on level 4. The unit is open from 9.00am to 5.00pm Monday to Sunday. Phlebotomy is carried out on this unit during these times and out of hours phlebotomy can be arranged by prior appointment.

Both units pride themselves on being very friendly and comfortable where patients and parents meet in a non-clinical, familiar environment. Children have the choice of comfortable recliner chairs or beds, adult patients have the use of sofas that convert to beds if preferred. Both units have televisions, DVDs and Wi-Fi and refreshments are offered throughout the patient's stay.

### Clinic times

Children are seen by both our consultant paediatrician and consultant haematologists so that all aspects of their sickle cell/thalassaemia and general development can be monitored using a holistic approach.

A paediatric sickle cell clinic is held every Monday between 2.30pm and 5.00pm and a paediatric thalassaemia clinic is held on a Thursday evening every two months between 3.30pm and 7.00pm in Clinic 4D, level 4

A paediatric nurse-led clinic is held every Wednesday between 2.00pm and 6.00pm where children and their parents can access expert advice and have their blood tests. A general paediatric clinic is held between 10.00am and 12.00pm (held in CAU level 2), Monday to Friday, where emergency treatment can be sought immediately. Patients can attend this clinic without an appointment; however it is advisable that parents/carers telephone ahead of their visit so that the clinic can prepare for the child's appointment.

Our adult sickle cell clinic is held every Tuesday between 9.00am and 1.00pm, and our adult thalassaemia clinic is held every Thursday between 3.30pm and 7.00pm. A joint diabetic/thalassaemia clinic is held every three months on a Thursday evening between 4.00pm and 7.00pm.

The clinics are held in clinic 3B (level 3 – outpatient department). A nurse-led clinic is available Monday to Friday between 9.00am and 5.00pm within the adult thalassaemia unit.

### Admission wards

Children requiring hospital admission are treated on Ifor ward (level 4). Visiting times are 8.00am until 8.00pm, one parent may stay overnight.

Adults are treated on Victoria ward (level 5), visiting times are 2.00pm until 8.00pm.



### How to change an appointment

To change an adult clinic appointment, please phone 020 7288 5144/5437 during Monday to Friday 9.00am to 5.00pm.

To change an appointment for the children's clinic please phone 020 7288 5882

### Community services

The sickle cell and thalassaemia community team, comprising a community matron, clinical psychologist and genetic counsellors, currently provide a range of services including antenatal and newborn screening, psychology support, social work referrals and health education and promotion. A drop in service is also available and service users can attend without a prior appointment.

This innovative service provides an integrated and personalised, high quality care package for people with haemoglobin disorders. We also work very closely with the Camden and Islington clinical health psychology team who have a long standing interest in the holistic treatment of sickle cell and thalassaemia disorders.

The community team is based at the Sickle Cell and Thalassaemia Centre which is located on Hornsey Street.

### Contacts

Should you require any help or advice outside of your clinic appointments, please contact:

#### Children

Haemoglobinopathy nurse specialist – 020 7288 3017/07799347161 (Monday to Friday 10.00am to 6.00pm) or alternatively Ifor Ward – 020 7288 5442 evenings and weekends.

#### Adults

Haemoglobinopathy nurse specialist – 020 7288 5225 (Monday to Friday 9.00am to 5.00pm) or alternatively Victoria ward – 020 7288 5444 evenings and weekends.

#### Dr Bernard Davis

Consultant Haematologist

Telephone: 020 7288 5437

Email: [bernard.davis1@nhs.net](mailto:bernard.davis1@nhs.net)

#### Dr Farrukh Shah

Consultant Haematologist

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#### Dr Emma Drasar

Consultant Haematologist

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**Dr Andrew Robins**

Consultant Paediatrician

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Consultant Paediatrician

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Consultant Diabetologist

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Paediatric Haemoglobinopathy Nurse Specialist

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Thalassaemia Nurse Specialist

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Sickle Cell Community Matron

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Mobile: 07920 711210 Email: [matty.asante-owusu@nhs.net](mailto:matty.asante-owusu@nhs.net)**Niamh Malone-Cooke**

Thalassaemia Unit Sister (adults)

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Email: [niamh.malone-cooke@nhs.net](mailto:niamh.malone-cooke@nhs.net)**Olivia Kudom**

Adult Sickle Cell Nurse Specialist

Telephone: 020 7288 5035

Email: [olivia.kudom@nhs.net](mailto:olivia.kudom@nhs.net)**Deborah Wellington**

Family Psychotherapist

Telephone: 07508377980

**Dr China Eziefula**

Clinical Psychologist

02075271538



**Children Ambulatory Unit**

Telephone: 02072883560/ 3561

**Rose Day Care Unit**

Telephone: 020 7288 3769

**Ifor Ward**

Telephone: 020 7288 5442

**Adult Thalassaemia Unit**

Telephone: 020 7288 5225

**Clinic 4D – Paediatrics**

Telephone: 020 7288 5882

**Clinic 3B – Adults**

Telephone: 020 7288 5331

**Sickle Cell and Thalassaemia Centre**

17a Hornsey Street, London N7 8GG

Telephone: 020 3316 8853/8854

Website: [www.islington.nhs.uk/Your-NHS-services/sickle-cell-and-thalassaemia.htm](http://www.islington.nhs.uk/Your-NHS-services/sickle-cell-and-thalassaemia.htm)

**Support groups and charities****Red Cells R Us**

Sickle Cell & Thalassaemia Centre

17a Hornsey Street

London N7 8GG

Telephone: 0203 316 8853/8854

Twitter: @Red Cells R Us

Facebook: Red Cells R Us

Google+: Red Cells R Us (in community section)

**Sickle Cell Society**

54 Station Road, London NW10 4UA

Telephone: 020 8961 7795

Website: [www.sicklecellsociety.org](http://www.sicklecellsociety.org)

**United Kingdom Thalassaemia Society**

19 The Broadway, Southgate Circus, London N14 6PH

Telephone: 020 8882 0011

Website: <http://ukts.org/>

**How to get involved**

The Camden & Islington Sickle Cell and Thalassaemia Service run a patient support group for patients with sickle cell and thalassaemia and their families and carers. The group is open to Whittington Health, University College London Hospitals or Royal Free Hospital patients with sickle cell or thalassaemia and is also open to residents of Camden and Islington.



For more information about the group including details of how to join, please phone: 020 3316 8853/8854, email [sicklethalcandi@nhs.net](mailto:sicklethalcandi@nhs.net) or visit <http://www.whittington.nhs.uk/default.asp?c=10885>

In addition patients can get involved with improving general patient experience at Whittington Health. Please visit: <http://www.whittington.nhs.uk/default.asp?c=11224> for further information.

### Healthwatch England

Skipton House, 80 London Road, London, SE1 6LH

Telephone: 03000 683 000

Fax: 01132 204702

Email: [enquiries@healthwatch.co.uk](mailto:enquiries@healthwatch.co.uk)

Website: [www.healthwatch.co.uk/](http://www.healthwatch.co.uk/)

Twitter: @HealthwatchE #thinkrights

### Patient advice and liaison service (PALS)

If you have a compliment, complaint or concern please contact our PALS team on 020 7288 5551 or [whh-tr.whitthealthPALS@nhs.net](mailto:whh-tr.whitthealthPALS@nhs.net)

If you need a large print, audio or translated copy of this leaflet please contact us on 020 7288 3182. We will try our best to meet your needs.

[Twitter.com/WhitHealth](https://twitter.com/WhitHealth)

[Facebook.com/WhittingtonHealth](https://facebook.com/WhittingtonHealth)

### Whittington Health NHS Trust

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