



Community sickle cell and thalassaemia services

A patient's guide

Introduction

The sickle cell and thalassaemia community services are an excellent source of support, contact, advice and advocacy for people with sickle cell disease and thalassaemia and their families. They are an essential part of the NHS antenatal and newborn screening programme, and offer advice to carriers about inheritance of these conditions.

Depending on their location, each service can differ in size from one person to a whole team of nurses, counsellors and other healthcare professionals.

The sickle cell and thalassaemia community centres are located in areas where sickle cell and thalassaemia are common. The service you can attend will depend on your borough and/or address.

Whittington Health provides support to people living in Camden and Islington. If you live outside of these boroughs, the team can advise you who may be able to support you, and on occasion they may be able to offer that support themselves.

Sickle cell and thalassaemia community services (Whittington Health)

All our sickle cell and thalassaemia community services put those with or at risk of a haemoglobin disorder at the centre of care.

They take a holistic approach to care, which means that they recognise and address the physical as well as the emotional and social needs of patients and families affected by sickle cell disease or thalassaemia.

The team consists of specialist PEGASUS nurses (Professional Education for Genetic Assessment and Screening), specialist practitioners and the community matron, clinical psychologist and administrative staff. They all aim to provide a high-quality personalised care for all service users.

The work of the sickle cell and thalassaemia community matron and clinical psychologist is also focused on improving community care for sickle cell patients with highly complex needs. Sometimes the community matron visits patients in hospital.



The team works closely with local hospitals, GPs and other primary care and community healthcare staff, and with local authorities. They also work in partnership with government and patient organisations.

Services on offer include:

- Specialist nursing service
- Genetic counselling to support the local antenatal and newborn screening programmes
- Psychological support in the community
- Testing of blood for sickle cell and thalassaemia, and other red blood cell types
- Pre-conceptual screening and counselling
- Health promotion
- School visits to educate staff teaching haemoglobin disorders
- School nurse training
- Education and training programmes for midwives, health visitors, medical students and pre-registration nurses
- Community awareness for the general public, health and non-health professionals
- Specialist support provided by the community matron to patients with highly complex needs
- Resource and information centres (leaflets, articles, DVDs)
- A 'drop-in' service so that patients with problematic issues have access to timely advice and support without an appointment.

Referrals to the service – the team accepts:

- Self-referrals (where you can refer yourself to the service)
- Referrals from health and non-health professionals
- Routine referrals via the national screening programmes.

Contacts

Specialist nurses

Matty Asante-Owusu (community matron, adults):	07920 711210
Edith Aimiuwu/Sarah Cullen (nurse specialist, children):	07799 347161
Emma Prescott (nurse specialist, thalassaemia):	020 7288 5225
Olivia Kudom (sickle cell nurse specialist, adults)	07887 987931

Haematology consultants

Dr Bernard Davis
 Dr Farrukh Shah
 Dr Ali Rismani
 Dr Emma Drasar

Paediatric consultants

Dr Andrew Robins
 Dr Janine Younis



Camden & Islington Sickle Cell and Thalassaemia Centre

17a Hornsey Street
Holloway
London N7 8GG

Tel.: 020 3316 8853/8854

Fax: 020 7690 3552

Website: <http://www.islington.nhs.uk/Your-NHS-services/sickle-cell-and-thalassaemia.htm>

Where can I get more information?

Red Cells R Us

Sickle Cell & Thalassaemia Centre
17a Hornsey Street
London N7 8GG

Tel.: 020 3316 8853/8854

Twitter: @Red Cells R Us

Facebook: Red Cells R Us

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

The Sickle Cell Society

54 Station Road
London NW10 4UA

Tel: 020 8861 7795

Website: www.sicklecellsociety.org

NHS Sickle Cell and Thalassaemia Screening Programme

<https://www.gov.uk/topic/population-screening-programmes/sickle-cell-thalassaemia>

The UK Thalassaemia Society

19 The Broadway
London N14 6PH

Tel: 020 8882 0011

Website: www.ukts.org



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

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.

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