

Sickle Cell and Thalassaemia Service (Adults): an overview of the service and useful information

This leaflet explains more about the adult sickle cell and thalassaemia service at St. George's Hospital. If you have any further questions, please speak to one of the team using the contact details listed towards the end of this leaflet.

What is sickle cell disease and what is thalassaemia?

Sickle cell disease (SCD) and thalassaemia are lifelong, inherited disorders that affect the red blood cells. They are sometimes called 'red cell disorders' or 'haemoglobin disorders'. Please see the trust leaflet called 'Information about sickle cell disease and thalassaemia (adults)' for more detail.

What is the sickle cell and thalassaemia service at St George's?

People can have different forms of SCD or thalassaemia, with varying needs and possible complications. Our service offers treatment, support and advice for all forms of these conditions, including medical treatment in our outpatient clinics, day units or on the hospital wards.

St George's is a specialist centre for SCD and thalassaemia. We offer a wide range of specialist treatment options, with services including:

- weekly multidisciplinary clinics (doctors, nurses and psychologists) for patients with SCD and thalassaemia to offer annual reviews, monitoring of treatments and reviews of pain and how things are going
- a full emergency department with a direct link to our specialist haematology team
- admission to a ward if specialised treatment is required
- close links to other specialties for screening and investigation (for eye, heart, kidney and urology tests and treatment)
- a specialist Haematology Day Unit for blood transfusions and red cell exchange treatments
- specialist clinical nursing staff
- a community nursing team in some boroughs
- a dedicated clinical health psychology service based within the haematology team for patients with SCD and thalassaemia
- specialist genetic screening and pre-conception advice
- close links with the paediatric (children's) haematology team
- a specialist haematology laboratory and blood service
- patient and family education and awareness workshops

- training and education for healthcare professionals from other specialties and from primary care.

We can also arrange the following services for you:

- Spiritual support through the hospital's multi-faith chaplaincy. There is a multi-faith prayer room located in St. James' Wing which can be used by patients or visitors to the hospital.
- An interpreter, if you would like language support – please let us know in advance of your appointment that you need an interpreter and let us know what language and any gender preferences.
- Hospital transport, if eligible – please call 020 8725 0808 for a telephone assessment and to book transport.

How can I be referred to St George's Hospital?

You can ask your GP to refer you to the sickle cell and thalassaemia consultant haematologist at St George's. If you receive your main care at another hospital, your consultant can refer you to us for specialist services.

Can I have blood transfusions at St George's and also be seen at my usual hospital?

Yes, this is fine. We have arrangements with many hospitals for their patients to come to our specialist Day Unit for blood transfusions and red cell exchanges. Equally we can often arrange for transfusions to be held at your local hospital if you travel to see us in clinic.

What if I have to come in to hospital for treatment?

If you are in a lot of pain or feel very unwell, come to our emergency department (A&E) where you will be assessed and given rapid treatment. One of the haematology doctors will also usually come to see you and will advise you on whether you need to be admitted to hospital or go home once you are feeling better. If you are away from St George's do go to the local emergency department and tell them that you have SCD or thalassaemia and you are looked after at St George's. They are able to contact us and we can offer advice.

If you come into hospital you will most likely stay on one of our haematology wards (Ruth Myles Ward or Gordon-Smith Ward). In some cases, you may be allocated beds on other wards where staff are familiar with the treatment of SCD or thalassaemia. You will still be under the care of the sickle cell and thalassaemia team who will come to review you wherever you are in the hospital.

What happens when I leave hospital?

When you are well enough to go home we will contact your GP to let him or her know you have been in hospital. If you live in the borough of Wandsworth, we can let the community clinical nurse specialist know that you have been an inpatient, so that they can contact you to make sure you have everything you need. We are also happy to let community nursing teams in other boroughs know that you have been an inpatient at St George's.

Out of hours and emergency contact

For urgent medical advice please come to the emergency department at St George's Hospital or your nearest A&E department if you are not near Tooting.

Ward, day unit and clinic details

Haematology wards	
<p>Ruth Myles Ward, St James Wing 2nd Floor Visiting hours: 3pm to 8pm daily Tel: 020 8725 2442 or 020 8725 3158</p>	<p>Gordon-Smith Ward, Lanesborough Wing 3rd Floor Visiting hours: 3pm to 8pm daily Tel: 020 8725 5897 or 020 8725 5873</p>
<p>Trevor Howell Ward, Lanesborough Wing 3rd Floor Visiting hours: 3pm to 8pm daily Tel: 020 8725 1082 or 020 8725 1083</p>	
<p>Haematology Day Unit (on Ruth Myles) Monday to Friday, 8.30am to 5pm for transfusions by appointment (your doctor or nurse will talk to you about these if you need them). Tel: 020 8725 1680</p>	<p>Apheresis Day Unit (on Gordon Smith Ward) Monday to Friday, 8.30am to 5pm for red cell exchange transfusions by appointment (your doctor or nurse will talk to you about these if you need them). Tel: 020 8725 0612</p>
<p>Outpatient clinics Tel: 020 8725 3535 (on the day of your appointment only)</p> <p>Wednesday afternoons – by appointment only. If you need to change an appointment, please call 020 8725 4370. To change clinical psychology appointments, please contact the psychologist directly using the numbers below.</p>	<p>Phlebotomy Lanesborough Wing Tel: 020 8725 1733</p> <p>Open 7.30am until 4.45pm Monday to Friday Phlebotomy will take your blood test before a transfusion or red cell exchange, unless you have a different arrangement with the team.</p>
<p>Red Cell Pain Management and Psychology Service Tel: 07798 581198 Monday to Friday, 9-5pm (physiotherapy appointments Mondays and Tuesdays only). Appointments at the Phoenix Centre and other locations in the hospital.</p>	

Contact information for key staff

Dr Elizabeth Rhodes (lead sickle cell and thalassaemia consultant)

Tel: 020 8725 0885

Dr Julia Sikorska (sickle cell and thalassaemia consultant)

Tel: 020 8725 0885

Carol Rose (clinical nurse specialist)

Tel: 07500 835735

Red Cell Pain Management and Psychology Service - Dr Jenna Love (clinical psychologist),

Ms Rebecca McLoughlin (specialist physiotherapist)

Tel: 07798 581198, **Email:** SCDpain@stgeorges.nhs.uk

Sickle cell and thalassaemia secretary

Tel: 020 8725 0885

Contact details for other services

Genetic screening and antenatal and pre-conception counselling

Tel: 020 8812 6236, Tooting Health Centre

Community sickle cell and thalassaemia clinical nurse specialists for local boroughs

- Wandsworth – 020 8812 6236. Leteshia Abrahams-Dixon. Tooting Health Centre.
- Sutton and Merton – no service currently
- Lambeth, Southwark and Lewisham – 020 3049 5993
- Croydon – 020 8251 7229. Paula Lindo. 316-320 Whitehorse Road.

Wandsworth sickle cell and thalassaemia support group

15 Broadwater Road, Tooting, London, SW17 0DS

Tel: 020 8682 9489 **Web:** www.wsctsg.org.uk **Email:** wsctsg@btinternet.com

Croydon Sickle Cell and Thalassaemia Support Group

316 Whitehorse Rd, Croydon, CR0 2LE

Tel: 020 8251 7259 **Web:** <http://cscats.org/wp/>

Sickle Cell Society

54 Station Road, London NW10 4UA

Tel: 020 8961 7795 **Web:** www.sicklecellsociety.org **Email:** info@sicklecellsociety.org

UK Thalassaemia Society

19 The Broadway, Southgate Circus, London N14 6PH

Tel: 020 8882 0011 **Web:** www.ukts.org **Email:** office@ukts.org

Other types of support

Support from social services

If you think you need help to cope day-to-day, the first step is to get a needs assessment from your local council. You'll need to have this assessment before the council can recommend a service such as:

- equipment like a walking frame or personal alarm
- changes to your home such as a walk-in shower
- practical help from a paid carer
- access to day centres and lunch clubs
- moving to a care home

The needs assessment is free and anyone can ask for one. Contact social services at your local council and ask for a needs assessment. You can call them or do it online.

Housing and benefits

The Citizen's Advice Bureau (CAB) can offer advice about what benefits you might be entitled to, how to apply, and support with completing forms. You can find details of your local branch online.

Citizens Advice Wandsworth's Disability and Social Care Advice Service (DASCAS) provides independent advice to residents of the London Borough of Wandsworth about disability and sickness benefits and services. Call on 0300 330 1169 Mon-Fri 10am-4pm for advice on disability and sickness benefits and services.

Turn2us has advice about benefits and grants. Their helpline is 0808 802 2000

If you need to apply for social housing, you will need to contact your local council, who can advise you about the process.

Shelter provides advice about housing and support for those at risk of homelessness. Their helpline is 0808 800 4444, and is open 8am to 8pm on weekdays and 9am to 5pm on weekends. They also have a lot of advice online www.shelter.org.uk

Immigration advice

The Citizen's Advice Bureau can offer advice about immigration issues.

CARAS is a community outreach charity based in Tooting who people of refugee and asylum-seeking background. You can contact them on 020 8767 5378

Feedback, Compliments and Complaints

If you would like to give feedback about the service you have received, or discuss a matter you are not happy with, you can speak to a member of the team or complete the feedback questionnaires that are given out at times throughout the year. You can also speak to the **Patient Advice and Liaison Service (PALS)**, as below.

You can also speak to **Healthwatch**, an independent consumer champion that gathers the views of, and represents, the public on matters of health and social care. The Wandsworth branch can be contacted on 020 8516 7767.

We are always keen for people who use our services to be involved in developing them; please contact a member of the team to discuss ways you can do this, including giving feedback on patient leaflets, helping to plan events like the workshops and celebration days we offer or getting involved in research.

Additional services

Patient Advice and Liaison Service (PALS)

PALS can offer you on-the-spot advice and information when you have comments or concerns about our services or the care you have received. You can visit the PALS office between 9.30am and 4.30pm, Monday to Friday in the main corridor between Grosvenor and Lanesborough Wing (near the lift foyer).

Tel: 020 8725 2453 **Email:** pals@stgeorges.nhs.uk

NHS Choices

NHS Choices provides online information and guidance on all aspects of health and healthcare, to help you make decisions about your health.

Web: www.nhs.uk

NHS 111

You can call 111 when you need medical help fast but it's not a 999 emergency. NHS 111 is available 24 hours a day, 365 days a year. Calls are free from landlines and mobile phones.

Tel: 111



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