

Universal Care Plans for Patients with Sickle Cell Disease

This leaflet provides information about your universal care plan. If you have any further questions or concerns, please speak to the staff member in charge of your care.

What is a Universal Care Plan?

A Universal Care Plan, often referred to as a UCP, is *'an NHS service that enables every Londoner to have their care and support wishes digitally shared with healthcare professionals across the capital. (1)'*

It was launched in 2022 and now covers a wide range of conditions, including sickle cell disease. After listening to the difficulties that patients report about accessing appropriate care at times, the aim was for services to create individual care plans that are accessible across the NHS.

The UCP aims to improve healthcare outcomes for sickle cell patients by enabling patients to feel confident that healthcare professionals looking after them will have access to important information including individualised care plans, regardless of which hospital in London they attend.

Your UCP will contain important information about you and your sickle cell disease that may be required by healthcare professionals.

Examples include.

- Preferred name and contact details including your address as well as contact details for your primary sickle centre.
- Current diagnoses including sickle genotype and significant medical history.
- Symptom management plan including a sickle pain crisis management plan for use in the emergency department.
- Any advance decisions to refuse treatment as well as end of life care wishes and decisions about CPR.

Who can see my UCP?

Healthcare and social care professionals in London, such as doctors and nurses, who are involved in your care will have access to your Universal Care Plan (4).

Can I see my UCP?

Yes, you can access your UCP via the NHS app. This can be viewed by opening the App and then going to Your Health > Care Plans > Universal Care Plan.

Can I discuss what is in my UCP?

Yes. If you want to discuss what is in your UCP please discuss this with a member of your haemoglobinopathy team. We will aim to discuss this with each patient during their annual review each year as well.

Do I have to have a UCP?

You can also refuse to have a UCP. We would strongly advise that you have a UCP as this means we can provide optimal care for your sickle cell disease.

We would advise that you discuss that this with your haemoglobinopathy team if this is something you are considering.

References:

(1): [About – Universal Care Plan](#)

(2) No One is Listening Report. [No One's Listening - A Report » Sickle Cell Society](#)

(3) [Universal Care Plan breaks usage records with new integrations and sickle cell care plans - Integrated Care Journal](#)

(4) [Patients – Universal Care Plan?](#)

Contact us

If you have any questions or concerns about your UCP, please discuss this with a member of the red cell haematology team at your next appointment or using the details below.

Dr Elizabeth Rhodes (sickle cell and thalassaemia consultant)

Tel: 020 8725 0885

Dr Julia Sikorska (lead sickle cell and thalassaemia consultant)

Tel: 020 8725 0885

Dr James Masters (sickle cell and thalassaemia consultant)

Tel: 020 8725 0885

EnaAbena Akomah-Barnier (clinical nurse specialist)

Tel: 07825 978812, Email: haemoglobinopathy.nurses@stgeorges.nhs.uk

Nazik Osei (clinical nurse specialist)

Tel: 07825 978812, Email: haemoglobinopathy.nurses@stgeorges.nhs.uk

Sickle cell and thalassaemia secretary

Tel: 020 8725 0885

For more information leaflets on conditions, procedures, treatments and services offered at our hospitals, please visit www.stgeorges.nhs.uk

Additional services

Patient Advice and Liaison Service (PALS)

PALS can offer you advice and information when you have comments or concerns about our services or care. You can contact the PALS team on the advisory telephone line Monday, Tuesday, Thursday and Friday from 2pm to 5pm.

A Walk-in service is available:

Monday, Tuesday and Thursday between 10am and 4pm.

Friday between 10am and 2pm.

The Walk-in and Advisory telephone services are closed on Wednesdays.

Please contact PALS in advance to check if there are any changes to opening times.

PALS is based within the hospital in the ground floor main corridor between Grosvenor and Lanesborough wings.

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

NHS UK

The NHS 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

AccessAble

You can download accessibility guides for all our services by searching 'St George's Hospital' on the AccessAble website (www.accessable.co.uk). The guides are designed to ensure everyone – including those with accessibility needs – can access our hospital and community sites with confidence.

