

Red Cell Pain Management and Psychology Service

This leaflet explains about the specialist pain self-management and psychology service for people with sickle cell disease and thalassaemia. If you have any further questions, please speak to one of the Red Cell team.

What is the Red Cell Pain Management and Psychology Service (RCPMPS)?

The RCPMPS is a service for people living with sickle cell disease or thalassaemia. The service is run by clinical psychologists and a specialist physiotherapist, who work closely with your haematology team.

There are two parts to the service: Pain Management and Psychology.

Pain Management

The specialist team has expertise in supporting people living with persistent pain thought to be related to their sickle cell disease or thalassaemia. Persistent pain is pain that you have regularly for longer than six months. It may also be called 'chronic' or 'everyday' pain.

There are several pain management services available, including:

- Individual appointments with psychology and / or physiotherapy to help you work towards your pain management goals, such as returning to valued activity or reducing mood difficulties associated with pain.
- Movement group a chance to try out some gentle exercise in a group and get advice from a physiotherapist about exercising safely with sickle cell disease / thalassaemia. You can attend occasionally or regularly, whichever suits you best.
- Pain Management Programme a more in-depth group programme which runs one day a week for eight weeks. The programme aims to help you develop additional ways to manage your pain and reduce the impact on your life. The weekly sessions provide an opportunity for discussion and to try out the exercises and strategies that we discuss. For more information, please see the leaflet *Breaking the Cycle: A Red Cell Pain Management Programme for people with sickle cell disease or thalassemia.*
- Red Cell pain clinic a doctor with experience in managing persistent pain (Consultant in Pain Medicine) will assess your pain and review your medication. You will decide with the doctor if any treatment changes would be helpful.

We think of our patients as the experts in their condition and hope that by working together we can help those living with persistent pain to reduce the impact on their emotional and physical wellbeing and carry on with the activities that are important to them.

Psychology service

The Psychologists in the RCPMPS seek to support you in coping with the multiple challenges that can come with living with sickle cell or thalassaemia. Speaking to a Psychologist can offer an opportunity to discuss the impact that your condition has on your quality of life.

Some of the most common areas that people choose to speak about with us include:

- Managing the impact that a long-term condition has on you
- Coping with hospital admissions
- Communicating with others about your condition.

The psychologist will meet with you for a first appointment to discuss what you feel you would like support with. Psychological support is usually offered as one to one sessions with the Psychologist.

The RCPMPS also offers a Red Cell Condition support group, which is an informal opportunity to speak about your experiences of living with sickle cell disease or thalassaemia, alongside others also living with Red Cell conditions. This is a monthly group and you can attend as often as you would find helpful.

If you are interested in any of the above options offered by the service, you can arrange to meet us for an initial assessment.

Social Prescribing Link Worker and Health and Wellbeing Coach

The Social Prescribing Service and Health and Wellbeing Service will be based within the Red Cell Pain Management & Psychology Service (employed by Merton Connected - Merton Social Prescribing team). The Social Prescriber will be working with patients affected by sickle cell disease and thalassemia, helping them connect to vital community services, to manage their health and reduce isolation. In addition, the Social Prescriber will:

- Use their coaching skills to support patients in developing self-management strategies, improving their health and achieving personal goals.
- Help reduce clinical workload by linking patients with local non-clinical services such as social activities, education, housing, employment support and more.
- Collaborate with multi-disciplinary teams and local agencies to build a robust referral network, ensuring patients have access to comprehensive support.
- Play a vital role in promoting the benefits of social prescribing and coaching to both clinical staff and patients, fostering a personalised care approach.

• Join a team committed to making lasting improvements in health outcomes, helping patients to regain control of their lives and offering support that goes beyond traditional medical treatment.

Full Circle Fund Therapies

Full Circle is a pioneer of holistic support in NHS hospitals for people of all ages with a life-challenging diagnosis. We provide evidence-based complementary therapies, free of charge, at the hospital bedside and through online resources.

Who can attend the service?

Anybody who is currently being seen by the St George's University Hospitals NHS Foundation Trust haemoglobinopathies team can be referred or self-refer, to our services. Please speak with your team about a referral or contact us via the details below to make an initial appointment.

We do accept referrals from other hospitals as we are a very specialised service. If you receive your care at another hospital, then please ask your haematologist or GP if they will refer you to the service.

Where do I need to go?

Sessions take place remotely and / or face to face at the Phoenix Centre on the perimeter road at St George's Hospital. See the website for a map or let us know if you need one.

Patient transport can usually be provided if you are eligible for this (you can call transport assessment and booking on 020 8725 0808) and there is blue badge parking near the Phoenix Centre. Please see the trust website for information on parking and travel by public transport.

Does it cost anything?

There is no charge for attending appointments with the service.

What do I need to bring with me?

You don't need to bring anything. You should wear comfortable clothes if you are attending the movement group.

Is there anything else to know?

We are a small service with limited numbers of appointments. If you do not come for your appointment and you don't let us know beforehand, it is much harder for us to give you and others a good service. Please let us know if you cannot make your appointment.

If we meet with you for an individual appointment, we will write a summary letter and send it to you, your haematology consultant and your GP. If you have concerns about this, please discuss this with us.

You can find out more about our service by visiting our YouTube channel. Search 'red cell pain management service' on YouTube to find our channel.

We work closely with the rest of the red cell haematology team at St George's Hospital and we will share relevant clinical information with the rest of the team when it might be useful for your medical care. Other than the letters mentioned above, information will not be shared outside the team unless there is a risk of harm to yourself or others. If you have any questions or concerns about confidentiality, please discuss them with us.

Useful sources of information

The British Pain Society has several publications for people living with long term pain: <u>www.britishpainsociety.org</u>

Contact us

If you have any questions or concerns, please contact the red cell pain management service on 07798 581 198 (Monday to Wednesday, 9am to 5pm). Alternatively, you can email us on <u>SCDpain@stgeorges.nhs.uk</u> or visit the St George's website at <u>http://tinyurl.com/SCDpain</u>

Please note - We do not offer an out of hours service. If you need urgent help, please contact your GP or go to your nearest emergency department (A&E).

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

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.



Reference: CLH_RCPM_04 Published: February 2025 Review date: February 2027