

Health Psychology Service for adults and young people with sickle cell disease and thalassaemia

This leaflet provides you with information about the service, how we can help you and how to contact us.

What is the Health Psychology Service (HPS)?

The HPS provides support for patients with haematological (blood) disorders at Guy's and St Thomas' NHS Foundation Trust. Founded in 1997, it now serves a large population of patients with sickle cell disease (SCD).

The HPS offers a variety of services for adults and young people (over the age of 16) with SCD and thalassaemia, as well as for their families.

Sickle cell disease refers to a group of genetic blood disorders that are associated with sickling of the red blood cells. Painful crises are the most common symptom of this condition and patients frequently need to stay in hospital for help with the management of their symptoms.

Thalassaemia refers to a group of genetic blood disorders that can cause anaemia. Patients with thalassaemia may need blood transfusions.

The HPS is led by health/clinical psychologists and is free to attend. Psychologists are trained healthcare professionals who help people manage their emotional concerns over a specific period of time. They **do not** prescribe medication.

HPS staff work with other members of the SCD team, including haematologists and nurse specialists, who are trained to meet the needs of patients with SCD and thalassaemia.

How can the service help me?

The psychologists can provide support and help you to:

- learn to live with SCD and thalassaemia
- cope with pain in hospital and at home
- adjust to being in hospital or having to come into hospital frequently
- deal with worries about your future
- manage family and relationship problems
- build your self-confidence
- deal with employment, career and educational concerns related to your condition
- cope with treatments
- communicate with nurses, doctors and other hospital staff
- cope with memory and concentration problems
- deal with a fear of needles or blood transfusions
- make decisions about your treatment options.

How does the service work?

If you would like psychological support, please speak to your nurse about a referral. You can also be referred by your GP, haematologist, school or voluntary organisation.

Alternatively, you can:

- contact the service yourself by phone or letter to request an appointment
- come to the SCD support group
- come to one of our drop-in clinics (see page 5 for more information).

What happens at my first appointment?

Your first appointment can take up to an hour. The psychologist will talk to you about your concerns and usual ways of coping with them. He/she will then make an assessment and tell you whether a series of psychological support sessions are likely to be helpful. The support sessions may be for you, your family or your partner.

Appointments are arranged between 9am and 5pm, Monday to Friday, usually for an hour. Depending on your concerns, you may have an appointment every one to two weeks. Appointments are held in the Department of Haematology at Guy's Hospital.

How we can help

Cognitive behavioural therapy

One important way that we can help patients is through Cognitive Behavioural Therapy (CBT).

In CBT, the psychologist helps you to identify problems and search for solutions. It helps you to link your thinking patterns, beliefs, emotions and behaviour. In addition to the sessions, you may also be given self-help assignments, for example keeping a diary to monitor your mood. These assignments can help you to learn to deal with your problems.

CBT focuses particularly on positive life skills, including:

- accepting your physical condition and limitations
- identifying your strengths, talents and weaknesses
- improving your self-confidence and self-esteem
- learning to put yourself in control of your illness

- understanding how your behaviour may affect your health and life.

The number of CBT sessions needed varies from person to person. You can stop seeing the psychologist any time you like, but we hope this will be after your concerns have been resolved.

About six months after you stop seeing the psychologist, we will write to you and invite you to come in for a follow-up appointment. This enables us to identify any new difficulties and provide further support, if needed.

Drop-in service

The HPS also offers a drop-in service where you can come in to see one of the psychologists without an appointment. The drop-in service is an opportunity for you to raise any concerns you might have. Following this discussion, you and the psychologist can decide the best way to help you with your concerns.

The drop-in service runs every Tuesday from 2pm to 3pm on a first come, first served basis. Please come to the reception desk, Department of Haematology, 4th Floor, Southwark Wing, Guy's Hospital.

Neuropsychological assessment

A neuropsychological assessment measures changes in your cognitive abilities, such as memory, concentration and problem solving. It shows what your strengths and limitations are, so we can work with you to find ways of coping. This can help you in your everyday activities, working life or studies.

For people with SCD, changes in cognitive abilities can be related to a variety of things. These include complications related to SCD, and mood changes such as anxiety, stress and depression.

Neuropsychological assessment is made up of several spoken, written and puzzle-type tasks. These are designed to assess skills and thought processes such as:

- reading ability
- memory
- language skills
- concentration
- problem solving skills
- perception (how you interpret what you see).

The length of assessment can vary, but normally takes about five hours. You can have the assessment in one day (with short breaks) or over a few separate appointments. After the assessment, we will invite you to a further appointment to discuss the results and explore ways for you to cope with your difficulties.

Confidentiality and privacy

Your visits are **private** and **confidential**. However, to improve the quality of the service you receive, we will inform the other members of the sickle cell team that you are receiving psychological support. We will also tell them when your therapy has ended. This is the only information that we will provide without your permission. If we want to talk to other people, for example your GP or tutor/employer, we will only do so **if you have agreed to it**.

The service regularly takes on trainee psychologists who are supervised by qualified staff and are given the opportunity to see therapy in practice. If you do not want students to be present, please let us know. Your wishes will always be respected and your care will not be affected in any way.

Support groups

The Sickle Cell Support Group for patients and their family members currently runs every Tuesday from 6pm to 7.30pm at Guy's Hospital. This takes place in the haematology seminar room in the Department of Haematology, 4th Floor, Southwark Wing, Guy's Hospital.

The aims of the support group are to:

- introduce psychological concepts and help participants manage stress
- link people suffering from SCD and share relevant issues, ideas, information, experiences, struggles and hopes
- give and receive support
- reduce fears, anxiety and the sense of isolation
- develop communication skills
- increase self-confidence and resources for coping with a serious illness.

Asking for and accepting support is not always easy. However, this confidential and non-judgemental group can help you to cope by listening, understanding, empathising and coaching you in the use of effective coping skills. This can be a great source of help to improve and sustain your or your family members' emotional wellbeing.

Who can I contact for more information?

If you would like to know more about the HPS for adults and adolescents with haematological and other blood disorders, please contact:

Dr Veronica Nicky Thomas, Head of Psychological Services/Consultant Health Psychologist

t: 020 7188 2725

e: nicky.thomas@gstt.nhs.uk

Dr Heather Rawle, Consultant Clinical/Health Psychologist

t: 020 7188 2718

e: heather.rawle@gstt.nhs.uk

Mina Abedian, Health psychologist

t: 020 7188 2718

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Department of Haematology

4th Floor, Southwark Wing

Guy's Hospital

Great Maze Pond

London SE1 9RT

Patient Advice and Liaison Service (PALS)

To make comments or raise concerns about the Trust's services, please contact PALS. Ask a member of staff to direct you to the PALS office or:

t: 020 7188 8801 at St Thomas' **t:** 020 7188 8803 at Guy's

e: pals@gstt.nhs.uk

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