

Psychology Service

for children 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.

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The Psychology Service and how it can help you/your child?

Our role is to provide psychological support to children and young people who are living with sickle cell disease (SCD) and thalassaemia, as well as support to their families/carers.

Children, young people, and their families can experience difficulties when trying to cope with the condition on a day-to-day basis. We are aware that living with SCD and thalassaemia can impact upon school, peer relationships, academic progress, and social and developmental aspects of growing up, and may limit your quality of life. We are also aware that difficulties in these areas can, at times, impact upon your emotional wellbeing and contribute to feelings of sadness, anxiety and worry. You may also experience feelings of being isolated from your peer group and/or family and friends, who may not understand how you are feeling. We believe that psychological support can be beneficial to finding effective ways to support children, young people, and their families with these challenges.

We can help you/your child with

- understanding and coping with the diagnosis
- working to improve adherence to medication
- coping with difficult feelings, eg stress, anxiety, low mood, uncertainty and other emotional difficulties
- pica (the consumption of non-food item)
- how to manage specific fears, eg of needles or blood transfusions

- managing hospital admissions or having to come in to hospital frequently
- how to cope with symptoms, eg pain, fatigue
- building self-confidence and self-esteem
- liaising with school to ensure they understand the diagnosis and can support you/your child
- neuropsychology assessments to help with difficulties found in progress and attainment in education
- support for families/siblings to understand the diagnosis
- coping with friendships and social life
- missed school and associated worry
- help to build a network of support.

How the service works

Clinics

The psychologist can join in clinics and is available to be part of clinic appointments with your doctor. They can give you more details about the psychology service and discuss with you and your doctor whether a referral would be suitable for you and /or your child.

Ward admission

The psychologist is available to support you/your child about being admitted and coping with being in hospital. If you feel this is needed, please liaise with the clinical nurse specialist or the doctor who sees you.

Outpatient appointments

Psychological support can be offered through individual and family sessions at hospital or school. In some cases, we may visit you at home. Psychology sessions will consist of an initial assessment appointment, where the psychologist will meet with you and your child to discuss the referral and current worries/concerns. This initial appointment can take up to 1.5 hours. As part of assessment, the psychologist will ask for your permission to liaise with other professionals – schools, community nurse, social care etc, if needed.

Following this assessment, a joint discussion will be held about whether therapy would be helpful. If this is agreed, you/your child will be invited to a number of outpatient appointments to begin therapy that will be arranged at a time that suits you/your child and the psychologist. If it is felt that therapy is not appropriate or needed, the psychologist can recommend other services that might be more useful.

During the course of therapy, the psychologist may recommend advice from other members of the children's psychological medicine team to help with assessment and support. If this is necessary, the psychologist will ask for your permission before asking a psychiatrist or another clinician from the team to join.

Liaison with school and community services

In addition to psychological therapy and support, we will often liaise with schools to ensure that children and young people are provided with the support needed they need to help with their education.

This can be given in many ways. We are able to provide neuropsychological/cognitive assessments that can help to inform educational health care plans (EHCP), as well as assess the overall learning and emotional support that a child or young person has in school.

In addition to formal assessments, we can also take a role in organising school meetings to review school health care plans along with your community nurse. We can assist schools in developing day-to-day strategies to support children and young people in school, particularly during more stressful periods such as exam times.

If you/your child is in hospital for a long time we can also help ensure the hospital school is in touch with you/your child's regular school to ensure any work is passed on.

Other community teams

Our role as part of the paediatric sickle cell and thalassaemia medical team also comes under a national and specialist service for South London and Maudsley (SLaM) Child and Adolescent Mental Health Services (CAMHS). This means that we can refer to their teams if needed. This could be for more specific assessment or treatment for your child's mental health, such as assessments for social communication difficulties, specific treatment for depression, anxiety, and other associated mental health diagnosis.

We also have good relationships with local community CAMHS teams, and can refer children, young people, and their families to these teams, if it is felt that this would be more helpful.

We work closely with community nurse specialists to help provide holistic care, and help with the management of your health and emotional needs.

Transition to adult teams

Psychological support might be needed to help families and young people to move from children's teams to adult teams. We know that this time can be a difficult and anxious time for young people, and their carers/families. As well as working closely with the transition nurse specialist, we also work with the adult SCD and thalassaemia psychology teams. We can help with the process of transferring you/your child's care to ensure a smooth transfer of care with ongoing psychological support, if required.

Out-patient appointment information

National and Specialist CAMHS Paediatric Liaison
Team/Children's Psychological Medicine
2nd Floor Gassiot House
St Thomas Hospital
Westminster Bridge Road,
London, SE1 7EH
t: 020 7188 9125

Contact us

Lead consultant for haemoglobin disorders, and consultant in haematology, t: 020 7188 6203 (secretary), **e:** Banu.Dudhma @gstt.nhs.uk

Lead nurse, t: 020 7188 9432 or 07918 338 730
e: HaemoglobinopathyCNS@gstt.nhs.uk

Nurse specialist, t: 07771 345847 or 07443 290973
e: HaemoglobinopathyCNS@gstt.nhs.uk

Research nurse, t: 020 7188 6637 or 07748 932743

Specialist nurse – community, t: 020 3049 5993 or 07880 781545

Therapy and psychology team, t: 020 7188 9125 or 07817 905844

Evelina London Medicines Helpline

If you have any questions or concerns about your child's medicines, please speak to the staff caring for them or contact our helpline. **t:** 020 7188 3003, Monday to Friday, 10am-5pm **e:** letstalkmedicines@gstt.nhs.uk

Your comments and concerns

For advice, support or to raise a concern, contact our Patient Advice and Liaison Service (PALS). To make a complaint, contact the complaints department.

t: 020 7188 8801 (PALS) **e:** pals@gstt.nhs.uk

t: 020 7188 3514 (complaints)

e: complaints2@gstt.nhs.uk

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