

The transition service for people with sickle cell disease

This leaflet explains more about the transition service for people with sickle cell disease. If you have any further questions, please speak to a doctor or nurse caring for you.

What is the transition service?

The transition service is a service involved in planning your care and supporting you to move from the children's to the adult hospital. As you have a chronic condition that will require ongoing treatment, it is important that you understand and prepare for the changes that you will go through as you grow and what they mean to your care. The transition team will discuss a number of issues with you. Their aim is to help you understand your condition better and to prepare you for the change over to adult services.

Who will I meet?

The key person and your first port of call is Luhanga Musumadi (transition specialist nurse). His role is to help you and your family to work out your healthcare management goals and what services you need in order to reach these goals. Patience Ologe is your community transition nurse and will support you with any issues in the community.

What exactly will happen to me?

All families are different, and what exactly will happen will depend on how much you as a young person are involved in taking care of your health. We want to make sure that when it is time to move on to the adult hospital, you have developed the right level of understanding and skills for adulthood. We also want to make sure that both you and your family feel confident about making the transition to adult services.

The transition team are the link between the children's and the adult hospital and they will work very closely to support you all the way until you are 24 years old (or until you feel settled into the adult hospital). This process begins with carrying out an initial assessment to understand your needs while you are still in the children's hospital at the age of 12 or 13. We will use the transition passport document questionnaire, which you can complete either on your own or with the help of either your parents/guardian or the transition specialist nurse.

The questionnaire will cover subjects like:

- your knowledge and understanding of your condition and treatment plans
- your ability to remember, without your parents' reminders, things like your appointments and taking medicines
- your ability to confidently ask and discuss issues concerning your health with your doctors and nurse
- how you feel about attending the adult hospital when the time comes.

Having sickle cell disease means you have ongoing healthcare needs. The psychology and community teams will also be working with you to support you with strategies to balance your illness with other areas of your life, such as studying, socialising, sports and hospital appointments.

Transition takes time and you will be supported to learn new skills that will help increase your independence and get you ready for adulthood.

Assessment stages

Stage I

When you are 12–13 years old, we introduce you and your family to the idea of the transition process.

Stage II

At 14–15 years, we aim to increase your understanding of your condition and the whole transition process by having more in-depth discussions and workshops.

Stage III

At 16–17 years, we would expect that all the years of working with you have paid off and you have a considerable degree of independence over your own care. By this stage, we hope that both you and your family feel confident about transferring your care to the adult hospital.

The transition clinic

Between 16 and 17 years old, you will be invited to attend the transition clinic where you and your family will have the opportunity to meet with the adult team, which includes the adult sickle cell consultant, the psychologists and a member of the community sickle cell team who will be involved in your future care. This clinic takes place in the Evelina Children's Hospital and the children's sickle cell consultant leads this clinic and makes the necessary introductions.

This clinic gives us the opportunity to discuss and plan how and when you are going to go over to the adult hospital. It is important to plan for this, both so that you are prepared, and so that you have time to say goodbye to all your carers in the children's hospital. Sometime before your first appointment with the adult doctors, you will be invited to an adolescent transition day, where you will have the opportunity to meet other young people in transition as well as others who have recently transitioned. You will also be able to take a guided tour of the adult hospital and meet the rest of the adult team.

Please remember to keep the contact details for your transition team in a safe place for when you need them.

What will happen when I am in the adult hospital?

Transition is a process that will continue over a number of years after you have moved to the adult hospital. Your transition team will work with you to ensure that your move is smooth and they will support you to adapt to your new environment until you feel that you have settled in.

Some of the things that they can help you with are:

- helping you to set and achieve goals
- advising you about services available to you
- talking to other services, including your school, university, or workplace, on your behalf about health issues
- helping to liaise with other clinicians and keep everyone informed about issues you might be concerned about
- providing you and your family with relevant information about the transition process
- helping you learn more about your condition and to become more independent in developing strategies to manage your life as you move into college, university and/or work.

Where do I need to go?

Your adult outpatient clinic is at Guy's Hospital in haematology clinic 2, 4th floor, Southwark Wing.

Further information

- www.scinfo.org
- www.youthhealthtalk.org
- www.transitioninfonetwork.org.uk
- www.connexions-direct.com
- www.teenagehealthfreak.org.uk
- www.sicklecellsociety.org
- www.haemoglobin-gstt.org

Pharmacy Medicines Helpline

If you have any questions or concerns about your medicines, please speak to the staff caring for you or call our helpline.

t: 020 7188 8748 9am to 5pm, Monday to Friday

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

Language support services

If you need an interpreter or information about your care in a different language or format, please get in touch using the following contact details.

t: 020 7188 8815 fax: 020 7188 5953

NHS Choices

Provides online information and guidance on all aspects of health and healthcare, to help you make choices about your health.

w: www.nhs.uk

Contact us

If you have any questions or concerns, please contact the sickle cell team on the following numbers between 9am and 5pm. If you have serious concerns outside these hours, please contact your local accident and emergency (A&E) department.

Paediatric consultant:

Dr Baba Inusa t: 020 7188 7774 (secretary)

Specialist registrar:

Bleep: 1139

Adolescent transition nurse specialist / Adolescent clinical nurse specialist:

Luhanga Musumadi t: 07770678851 **Bleep:** 2256)

CAMHS Practitioner

Jo Levitt t:020 7188 9125

Paediatrics clinical nurse specialist

Giselle Padmore-Penistone t: 020 7188 9432 m: 07771345847 **Bleep:** 2733

Community nurse counsellor:

Emma Gedeon, Theresa Oyiadjo and Patience.Ologe (Wooden Spoon House)
t: 020 3049 6068

Adult consultant haematologists:

Dr Jo Howard and Dr Rachel Kesse-Adu t: 020 7188 2741 (secretary)

Advanced nurse practitioner:

Mr Neil Westerdale t: 07770683947 **Bleep:** 1843)

Clinical nurse specialist:

Judith St Hilaire t: 020 7188 2710 m: 07920711266 **Bleep:** 2868

Psychologists:

Dr Nicky Thomas (Consultant Health Psychologist) t: 020 7188 2725

Dr Heather Rawle (Clinical Health Psychologist) t: 020 7188 2718

Mrs Mina Abedian (Health Psychologist) t: 020 7188 2718

Haematology clinic: t: 020 7188 2743 / 2724

Haematology day unit: t: 020 7188 2745

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