

Transition service for people with sickle cell disease and thalassaemia

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

The transition service is involved in planning your care, and supporting your move from the children's to the adult's hospital. As you have a chronic (long-term) condition that will need ongoing monitoring, it is important that you understand and prepare for the changes you will go through and what that means for your care. The transition team will discuss a number of issues with you. They will help you to understand your condition better and to prepare you to move to adult services.

Why you have to move

We understand that you have been coming to Evelina London Children's Hospital for many years, and that moving can feel daunting. You are becoming a young adult and will need care from adult-trained doctors and nurses who can meet your care needs. Adult services will be the best place for you to get the right medical care. By talking about transition early, it allows plenty of time for you to ask questions and discuss any concerns before the time to move to adult services arrives.

Who will help you get ready?

The children's clinical nurse specialists (CNS) and child and adolescent mental health team (CAMHS) are available for support and help during the transition process. The transition nurse practitioner will also help, and be the key person and first person to contact when you have moved to the adult service.

What will happen

All families are different, and what exactly will happen to you will depend on how much you are involved in taking care of your health. We want to make sure that when it is time to move to the adult hospital, you have developed a good level of understanding and skills for adulthood. We also want to make sure that 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 hospitals and they will work closely to support you until you feel settled in the adult service. This process begins with an 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 on your own or with the help of your parents or guardian, or with the transition specialist nurse.

The questionnaire will cover subjects like:

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

Having sickle cell disease or thalassaemia means you will need ongoing healthcare monitoring. The psychology and community teams are available to support you with strategies to balance your illness with other areas of your life, such as studying, socialising, hospital appointments and work.

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

When transition begins and ends

There are 3 stages of the transition process:

Stage 1

When you are 12 or 13 years old, we talk to you and your family about the transition process.

Stage 2

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

Stage 3

At 16 or 17 years old, we would expect that all the years of working with you have given you a good degree of independence over your own care. By this time, we hope that you and your family feel confident about transferring your care to the adult hospital. The transition clinics happen at this stage

The transition clinic

Between 16 and 17 years old, you will be invited to come to the transition clinic where you and your family will have the opportunity to meet with the adult team. This includes the adult haematology consultant, and psychologists. This clinic takes place at Evelina London and the children's haematology consultant leads this clinic and makes the necessary introductions. The children's specialist nurse and psychologist will also be there as well as the transition nurse, so there will be a few people in the room.

At the clinic we discuss and plan how and when you are going to move over to the adult hospital. It is important to plan for this so that you are prepared, and so that you have time to say goodbye to all your carers in the children's hospital.

We also run 1 or 2 workshops each year for all young adults who are undergoing transition. These include finding out more about Guy's Hospital and the adult sickle team. We also have young adults who have recently transitioned come in, to talk to you and your parents.

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

The transition team

Transition is a process that will continue over a few years after you have moved to the adult hospital. Your transition team will work with you to help make the move as smooth as possible, and they will support you to adapt to your new environment. Much like the children's hospital, you will come to the adult hospital for your clinic appointments and to the Day Unit if you have transfusions. There are also haematology inpatient wards just like at Evelina London. Although it might feel daunting, remember that the adult team are made up of doctors, nurses and psychologists who want to work with you, to support and care for you, just like the children's team.

Some of the things that the transition and adult team can help you with are:

- setting and achieving 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
- learning more about your condition, and becoming more independent in developing strategies to manage your life as it changes.

Where you need to go

Adult sickle and thalassaemia services are at Guy's Hospital at London Bridge. The adult outpatient clinic is in the Tabard Annexe on the ground floor.

The adult haematology day unit (where patients receive transfusions, and the pain service is based) is in Haematology 2, 4th floor, Southwark Wing.

There are several adult haematology wards at Guy's Hospital. For emergency treatment you will still go to St Thomas hospital, but you go to the adult emergency department (A&E) instead of the children's section.

If you move away from home

As you get older and gain independence, you might want to move away from home, for university or work, and your condition should not stop you. However, if you move away it is important that you let us know so we can co-ordinate ongoing care. Regular check-ups are essential to make sure you stay healthy, and we will need to refer you to a haematologist near your new home, who can continue to monitor you.

If you go away to university, you can still see the team at Guy's Hospital who can schedule your appointments to be during university holidays. However, it is important for you to have a doctor, who knows about your condition, near your university, so that they can help if you become unwell while you're there.

Support and more information

The Sickle Cell Society, [web www.sicklecellsociety.org](http://www.sicklecellsociety.org)

UK Thalassaemia Society, [web https://ukts.org/healthtalk](https://ukts.org/healthtalk), [web https://healthtalk.org/](https://healthtalk.org/)

Council for disabled children,
[web https://councilfordisabledchildren.org.uk/www.connexions-direct.com](https://councilfordisabledchildren.org.uk/www.connexions-direct.com)

Contact us

If you have any questions or concerns, please contact the sickle cell and thalassaemia teams on the numbers below, 9am to 5pm, Monday to Friday. If you have serious concerns outside these hours, please contact your nearest emergency department (A&E).

Children's team:

Consultants, **phone** 020 7188 6203 (secretary),
email gst-tr.ELCHPaedHaemoglobinopathyReferrals@nhs.net

Clinical nurse specialists (CNSs), **phone** 07771 345 847 or 07443 290 973,
email haemoglobinopathyCNS@gstt.nhs.uk

Therapy and psychology team, **phone** 020 7188 9125

Adult's team:

Consultant haematologists, **phone** 020 7188 2741 (secretary)

Clinical nurse specialists for sickle cell and thalassaemia, **phone** 0207 188 7188 extension 81424 or 52780, **bleep** 1843 or 2256, **mobile** 07548 152 680
email SickleCNSANPTeam@gstt.nhs.uk

Psychology team, **phone** 020 7188 2718, **email** HPS@gstt.nhs.uk

Haematology clinic appointments, **phone** 020 7188 2743/ 2724

Haematology Day Unit, **phone** 020 7188 2743

Community sickle cell and thalassaemia nurses, **phone** 020 3049 5993

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

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, **phone** 020 7188 3003, Monday to Friday, 10am to 5pm
email letstalkmedicines@gstt.nhs.uk

Your comments and concerns

For advice, support or to raise a concern, contact our Patient Advice and Liaison Service (PALS), **phone** 020 7188 8801 **email** pals@gstt.nhs.uk. To make a complaint contact the resolution department **phone** 020 7188 3514 **email** complaints2@gstt.nhs.uk

Language and accessible support services

If you need an interpreter or information about your care in a different language or format, please get in touch, **phone** 020 7188 8815 **email** languagesupport@gstt.nhs.uk

NHS 111

This service offers medical help and advice from fully trained advisers supported by experienced nurses and paramedics. Available over the phone 24 hours a day, **phone** 111
web www.111.nhs.uk

Leaflet number: 3035/VER3

Date published: July 2022 Review date: July 2025
© 2022 Guy's and St Thomas' NHS Foundation Trust