



# Transition to adult sickle cell and thalassaemia service

# Information for patients

This leaflet explains what happens when you reach an age when you begin to think about moving from children's sickle cell and thalassaemia care to the adult service. This process is called transition.

#### What is a transition?

Life involves many changes, especially for teenagers and young adults. These can include:

- moving from primary school to secondary school
- moving from secondary school to university
- starting full-time work
- moving out of home into your own place or a shared house.

These important events are about moving on, and are often called transitions.

#### How do transitions feel?

Transitions can be exciting and enjoyable; they can also be quite stressful. Do you remember how it felt when you started secondary school? It was probably exciting and scary at the same time. Just as you plan for secondary school, university or starting work, it is also important to plan your move from child to adult services.

# What will happen?

Transition is a gradual process. We will spend time talking with you about what sort of care and support you will need when you move to the adult service. For example, how ready you feel to make the move and when you will make it.

The Transition Clinical Nurse Specialist (CNS) will be the key person helping you with this. They will help you and your family through the process, answer your questions and advise you about any other help you may need. They will also agree a transition plan with you, to support you through this process.

### What is a transition plan?

This supports you through your transition and includes:

- Your health care needs.
- What you know and understand about your condition.
- How confident you feel about managing the different aspects of your condition. For example, talking to your medical team and organising your medications.
- Ways of building your confidence and independence so you can manage your own health.
- Your plans for the future.

#### **Key stages**

#### 13-14 years

We will start to talk with you about the transition process when you come to your usual clinic appointments.

#### 15-16 years

We start to work with you to develop yourskills in managing and taking more responsibility for your own health. We will talk more with you about the transition process, discuss any help you might need and start to make plans for your move to adult health care. This might include meeting with you individually, inviting you to workshops with other teenagers, visiting the adult wards and clinic areas, or helping you to get in contact with other services.

#### 17-18 years

We start to make detailed plans with you about your move to adult health care: where you will move to and when. If you decide to stay at King's College Hospital, you will meet and get to know the adult haematology team who will take over your care once you have moved.

## Adult Sickle Cell and Thalassaemia service team

The team includes:

- Consultant Haematologists
- Sickle cell disease and thalassaemia Clinical Nurse Specialists
- Transition Clinical Nurse Specialist
- Haematology Specialist Registrars
- Community Nurse Specialists.

#### How can I find out more about the transition service?

If you would like to talk to someone about transition, please contact the Transition Clinical Nurse Specialist.

Tel: 020 3299 1424

#### More information

**Sickle Cell Society** sicklecellsociety.org

**UK Thalassaemia Society** ukts.org

**healthtalk.org** www.healthtalk.org

#### YoungMinds

www.youngminds.org.uk

# **Sharing your information**

We have teamed up with Guy's and St Thomas' Hospitals in a partnership known as King's Health Partners Academic Health Sciences Centre. We are working together to give our patients the best possible care, so you might find we invite you for appointments at Guy's or St Thomas'. To make sure everyone you meet always has the most up-to-date information about your health, we may share information about you between the hospitals.

#### Care provided by students

We provide clinical training where our students get practical experience by treating patients. Please tell your doctor or nurse if you do not want students to be involved in your care. Your treatment will not be affected by your decision.

#### **PALS**

The Patient Advice and Liaison Service (PALS) is a service that offers support, information and assistance to patients, relatives and visitors. They can also provide help and advice if you have a concern or complaint that staff have not been able to resolve for you. The PALS office is located on the ground floor of the Hambleden Wing, near the main entrance on Bessemer Road - staff will be happy to direct you.

Tel: 020 3299 3601 Fax: 020 3299 3626

Email: kch-tr.PALS@nhs.net

You can also contact us by using our online form at www.kch.nhs.uk/contact/pals

If you would like the information in this leaflet in a different language or format, please contact PALS on 020 3299 1844.

www.kch.nhs.uk PL 665.1 March 2015

Corporate Comms: 1062 Review date March 2018

King's College Hospital is part of King's Health Partners Academic Health Sciences Centre (ASHC), a pioneering collaboration between King's College London, and Guy's and St. Thomas', King's College Hospital and South London and Maudsley NHS Foundation Trusts.