Transition from paediatric to adult services for individuals with Sickle Cell Disease

Patient information factsheet

This is a leaflet that explains how the Whittington Hospital Sickle Cell Team can work with you and your family to ensure a smooth transition to adult services.

Who is involved in this transition process?

The team…

- Dr Janine Younis – Consultant Paediatrician
- Dr Arpana Soni-Consultant Paediatrician
- Dr Emma Drasar – Consultant Haematologist
- Dr Ryan Mullaly – Consultant Haematologist
- Mrs Edith Aimiuwu– Haemoglobinopathies Nurse Specialist
- Ms Emma Savie-Disu- Haemoglobinopathies Nurse Specialist
- Dr Angelica Titmus - Clinical Psychologist
- Matty Asante-Owusu – Sickle Cell Community Matron
- Grace Adjei- Clinton - Community Haemoglobinopathies Nurse and Counsellor
- Sydney McCarthy–Burrell – Adult Haemoglobinopathy Community Nurse Specialist
- Nicola Nkwocha / Olivia Kudom – Adult Clinical Haemoglobinopathy Specialist Nurses

Paediatric outpatient service

- As you are aware, routine multi-disciplinary clinic reviews are arranged every 3 to 12 months with each young person attached to the paediatric haematology clinic. These clinic appointments are led by a Consultant Paediatrician and provide a forum in which honest explanations of Sickle Cell Disease (SCD) and individual health needs can take place.
- Young people and their parents/carers are encouraged to ask questions and are supported in making informed decisions about their health care.
- As you move through your teens, you may sometimes prefer to see a team member alone (even without your parents), especially when discussing subjects of a sensitive or emotional nature. Please do ask if you would like to arrange this.

Transition process

- The transition process is introduced in clinic discussions well before the actual change, typically when individuals reach their early teens. Careful planning with the young person and their family ensures a smooth and gradual transition to adult services.
- Starting around age 12, young people attend a joint paediatric and adult clinic, known as the transition clinic.
- During these appointments, they are seen by both adult and children's doctors and can ask questions, discuss their health needs, address transition concerns, and, if desired, be seen alone without parents or carers.
- Once they turn 18, young people transfer to the Adult Sickle Cell clinic. Some individuals will continue to need support even after formally transferring over to the adult clinic.
- For this reason, the paediatric haemoglobinopathy Nurse is available for one year post-transition to assist with any concerns or challenges.

Transition workshops

- Regular transition workshops are organized by the haemoglobinopathies Nurse Specialist, the Clinical Psychologist and the Sickle Cell Counsellor and are offered to all adolescents aged 16-18 years.
- These workshops aim to aid the process of transition by providing information about the adult service (using a quiz to make learning much more fun), giving a tour of the relevant adult units (pharmacy, A&E, adult clinics and wards etc.), introducing key staff members (e.g. ward staff), facilitating a discussion of concerns, inviting 'graduates' of the paediatric service to share experiences and transition 'tips', and providing a forum for peer support and sharing of coping strategies.
- Prior to the workshop, young people will be sent a questionnaire to complete, which covers
    - ➢ 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.
    - ➢ Managing emotions and transitioning to adult services

Additional internet website information sources are provided (e.g. www.youthhealthtalk.org & www.transitioninfonetwork.org.uk

Inpatient services

- Below is a table that highlights the major key differences between the adult and paediatric settings.

	Childrens and Young People Service	**Adult Sickle Cell Service**
Attends hospital with ambulance	Assessed in A&E	Assessed in A&E
Painful/sickle cell crisis that cannot be managed at home?	Can contact the paediatric department- specialist nurses, paediatric ward for advice or attend the Children's Ambulatory department for medical assessment.	Attend A&E for assessment. A care plan will be devised for you and remain in your records, which documents the nature of your condition and medical management.
Admitted to the Whittington hospital?	Admitted to Ifor ward	You will be admitted to Thorogood ward or another adult ward if no bed is available on Thorogood ward.

- Remember that the paediatric haemoglobinopathy Nurse is available for support during one year post-transition, if needed.
- The friendly adult team and ward Nurses are always happy to help young people transitioning, so just ASK.

And finally…

- Please remember that the Sickle Cell Team are here to help make your transfer as successful as possible.
- If at any time you have any concerns and/or want to know more, please make sure you let us know.

Contacts

Switchboard	020 7272 3070
Paediatric outpatients	020 7288 5883
Children’s clinical nurse specialist	020 7288 3017
Paediatric secretaries	020 7288 5616
Paediatric registrar on-call	Bleep 3111
Ifor Ward (Paediatrics)	020 7288 5442
Adult outpatient clinic	020 7288 5144
Adult Sickle Cell Specialist Nurse	020 7288 5035 / 07887987931

Patient advice and liaison service (PALS)

If you have a compliment, complaint or concern please contact our PALS team on 020 7288 5551 or whh-tr.PALS@nhs.net

If you need a large print, audio or translated copy of this leaflet please email whh-tr.patient-information@nhs.net. We will try our best to meet your needs

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