



Transition from paediatric to adult services for individuals with sickle cell disease

Are you (or your child) living with Sickle Cell Disease (SCD)?
Are you (or your child) midway through your teenage years?
If yes then you may already have started thinking about the future transfer of your SCD care to the adult service.

Here is a leaflet that explains how the Whittington Hospital Sickle Cell Team can work with you and your family to ensure you make this transition in the best possible way.

Who is involved in this transition process?

The team....

Dr Andrew Robins (A.R.) - Consultant Paediatrician
Dr Janine Younis (JY) - Consultant Paediatrician
Dr Bernard Davis (B.D.) - Consultant Haematologist
Ms Edith Aimiwu (E.A.) - Haemoglobinopathies Nurse Specialist
Chinea Eziefula (C.E) - Clinical Psychologist
Grace Adjei- Chukwu (G.A) - Sickle Cell Counsellor

Paediatric outpatient service

As you are aware, routine multi-disciplinary clinic reviews are arranged every three to twelve months with each young person attached to the paediatric haematology clinic. These clinic meetings are led by a consultant paediatrician (A.R.) and provide a forum within 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 into clinic discussions well in advance of the actual transition often when an individual has just reached their early teens. Careful thought is given to planning with the young person and family in order to ensure that a smooth gradual transition to the adult service can be achieved.



A consultant haematologist (B.D.) works in both the paediatric and adult haematology teams and thus each patient meets with him regularly during routine paediatric outpatient reviews. At about 15 years old each young person is invited by the haematologist to clinic appointments with the adult team. During these meetings you can ask questions, discuss transition issues and concerns and meet with the adult haematology team. The transfer usually occurs when you reach 18 years; however, the exact transfer date remains flexible in order to ensure that the specific needs of each adolescent are addressed.

It is recognised that many individuals continue to need support with regard to their transition even after they have formally moved to the adult clinic and thus care is taken to provide this support. The paediatric Haemoglobinopathies Nurse Specialist (E.A.) remains available to each adolescent for one year post-transition should you need to discuss or require help with your experiences in the adult clinic.

Transition workshops

Regular transition workshops are organized by the Haemoglobinopathies Nurse Specialist (E.A.), the Clinical Psychologist (C.F.) and the Sickle Cell Counsellor (G.A.) and are offered to all adolescents aged 16-18 years. These workshops aim to aid the process of transition through 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. Additional internet website information sources are provided (e.g. www.youthhealthtalk.org & www.transitioninfonetwork.org.uk)

Inpatient service

The clinic ethos is to avoid hospital admission where possible through educating about pain crisis prevention and enhancing self-management coping skills. As you are aware, children and adolescents who are experiencing severe pain crises that cannot be managed at home (or other SCD-related complications) can telephone /present to the paediatric department with an emergency card (that entitles you to a medical assessment without the need for an A&E or GP referral).

Once you have transferred your care to the adult service, you will need to present at A&E when requiring hospital attention. A 'care plan' will be made available in your medical notes which document the nature of your condition and the recommended medical management. In this way emergency staff can attend to your medical needs as quickly as possible with minimal explanation required by you.

When admitted as an inpatient, adolescents under 18 years old stay on the paediatric Ifor ward. From 18 years old and upwards, you are admitted to the adult (Victoria) ward or other adult wards when there are no beds on Victoria.



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.

We may also arrange other tests as well, such as a brain scan called an MRI (Magnetic Resonance Imaging and Angiography), which is another painless scan to check the brain and its blood vessels in more detail. We will talk to you and explain what the results mean and what treatment options are available.

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

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.whithealthPALS@nhs.net

If you need a large print, audio or translated copy of this leaflet please contact us on 020 7288 3182. We will try our best to meet your needs.

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Whittington Health NHS Trust
Magdala Avenue
London
N19 5NF
Phone: 020 7272 3070
www.whittington.nhs.uk



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Date published: 07/02/2019
Review date: 07/02/2021
Ref: CYP/PaedHaem/TPASISCD/01

