

Children's Haemoglobinopathy

Moving from children to adult services – A guide for young people with sickle cell anaemia or thalassaemia

Transition into adult services

Transition is the process of transferring a young person's care from the children's (paediatric) to the adult service. The process isn't fixed, and we will help you prepare for a gradual move to the adult service.

The exact timing will depend on your circumstances and preferences, but will usually start between the ages of 12-13 years, with full transfer to the adult services by 16 years.

To begin with, during your clinic appointments, your paediatric consultant and specialist nurse will talk to you about general aspects of your health. As you get a little older, these discussions will become more detailed. You will be encouraged to ask questions about your health to help increase your understanding and confidence about your condition.

Sickle cell anaemia

If you have sickle cell anaemia, your paediatric consultant and nurse specialist will talk to you about various issues including:

- Your understanding of your sickle cell anaemia and how you inherited it.
- What can trigger a sickle cell crisis



Patient Information

- Why it is important to take daily medication such as Penicillin V and Folic Acid to prevent infections and anaemia.
- Why it is important for you to have health checks, blood tests, eye tests and visit the dentist.
- Why we will also check and monitor your heart and kidneys when you are an adult.
- Why you might need to take hydroxycarbamide, Exjade or to have regular blood transfusions.

Beta thalassaemia major

If you have beta thalassaemia your paediatric consultant and nurse specialist will discuss with you various issues including:

- Your understanding of thalassaemia and how you inherited it.
- What might be a serious complication for you, such as severe stomach pain and fever.
- Why you might need to take medicine if you have too much iron in your body. (Iron chelation medication such as Exjade).
- Why it is important for you to have health checks for your bones, heart and liver, and to have eye and hearing checks.

Sickle cell anaemia and beta thalassaemia major

We may talk about:

- Planning to start a family and contraception to stop you becoming pregnant.
- Your plans after leaving school, for example further education, training or getting a job.
- How your care will continue if you move away from Coventry.
- Taking charge of your health as a young adult and making healthy lifestyle choices.
- Additional vaccinations.

Patient Information

Getting to know the adult service

Your nurse specialist will arrange for you and your family to meet with the adult specialists. You will then have a chance to visit the adult Haematology unit and clinic on Ward 34 so you will know where you are going before your actual transition to the adult service.

The adult Sickle Cell and Thalassaemia service is different from the children's service because the team will treat you as a young adult and not as a child. Parents or guardians may wish to come with you for the first appointment to see your new consultant and nurse. However, eventually we will encourage you to attend by yourself.

Don't worry - we encourage your parents or guardians and family to be around to give you support when you need it.

Making a date for transition

Before your 17th birthday, a definite date will be made for you to be transferred to the adult service.

Before any clinic appointment

List or bring with you all your medicines and pills — including vitamins and supplements.

Write down any questions that you may want to ask the doctor.

You can ask a friend or family member to come with you, if you like.

During your appointment

Don't be afraid to ask if you don't understand. For example, "Can you say that again? I still don't understand."

If you don't understand any words, ask for the words to be written down and explained.

If you find it difficult to remember, write things down, or ask a family member or friend to take notes.

Patient Information

Haemoglobinopathy Team at UHCW NHS Trust

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Melvis Nkamani – Adult Haemoglobinopathy Nurse Specialist

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Other resources

www.connexions-direct.com

www.sicklesociety.org

www.ukts.org

www.cdc.gov/features/sickle-cell-transition/index.html

The Trust has access to interpreting and translation services. If you need this information in another language or format, please contact and we will do our best to meet your needs.

The Trust operates a smoke free policy.

Patient Information

Did we get it right?

We would like you to tell us what you think about our services. This helps us make further improvements and recognise members of staff who provide a good service.

Have your say. Scan the QR code or visit:
www.uhcw.nhs.uk/feedback



Document History

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