

Paediatrics

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

Moving into adult services

Transition is the process of moving your care from the children's (paediatric) service to the adult service. This process is flexible, and we will support you to make a gradual move to adult care.

The exact timing will depend on your needs and preferences, but it usually starts between ages 12 and 13, with full transfer to adult services by around 16 years old.

At first, during your clinic appointments, your paediatric consultant and specialist nurse will talk to you about general aspects of your health. As you get older, these discussions will become more detailed. You will be encouraged to ask questions about your health to help build your understanding and confidence in managing your condition.

Sickle cell anaemia

If you have sickle cell anaemia, your paediatric consultant and specialist nurse will talk to you about several important topics, including:

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



Patient Information

- Why it is important to take daily medicines such as penicillin V and folic acid to help prevent infections and anaemia.
- The importance of regular health checks, blood tests, eye tests, and dental visits.
- Why your heart and kidneys are checked and monitored as you get older.
- Why you might need to take medicines such as hydroxycarbamide or exjade or have regular blood transfusions.

Beta thalassaemia major

If you have beta thalassaemia major, your paediatric consultant and specialist nurse will talk to you about:

- Your understanding of thalassaemia and how it is inherited.
- Possible serious complications, such as severe stomach pain or fever.
- Why you may need to take medicine to remove extra iron from your body, for example, iron chelation treatment such as exjade.
- The importance of regular health checks for your bones, heart, liver, eyesight, and hearing.

Sickle cell anaemia and beta thalassaemia major

We may also talk to you about:

- Contraception and family planning options.
- 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 responsibility for your health as a young adult and making healthy lifestyle choices.
- Any additional vaccinations you may need.

Patient Information

Getting to know the adult service

Your nurse specialist will arrange for you and your family to meet the adult specialists. You will also have a chance to visit the adult haematology unit and clinic on Ward 34, so you know where to go before your transition to adult services.

The adult sickle cell and thalassaemia service is different from the children's service because the team treats you as a young adult, not as a child. Parents or guardians may wish to come with you to the first appointment to meet your new consultant and nurse. After this you will be encouraged to attend appointments by yourself.

Don't worry – parents, guardians and family can still be there to support you when needed.

Making a date for transition

Before your 17th birthday, a definite date will be set for your transfer to the adult service.

Before any clinic appointment

- Make a list of all your medicines, including vitamins and supplements and bring it with you.
- Write down any questions you 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 something. For example, you could say, "Can you say that again? I still don't understand."

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

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

Patient Information

Haemoglobinopathy team at UHCW NHS Trust

Paediatric consultants

Dr Muhammad Farooqi and Dr Kim Neuling

Tel: 024 7696 7234

Paediatric ANP for Haematology and Oncology

Kate Norton

Tel: 024 7696 7291

Paediatric Haemoglobinopathy clinical nurse specialists

Vicki Hagger and Elle Lakhani

Tel: 024 7696 7225

Mobile: 0787 668 1069

Adult Haematology consultants

Dr Sarah Nicolle and Timothy Moorby

Tel: 0247 696 5539

Adult Haemoglobinopathy nurse specialist

Melvis Nkamani and Amanda Pearson

Tel: 0247 696 5544

Other resources

The Sickle Cell Society

54 Station Rd, London, NW10 4UA

Tel: 020 8961 7795

Website: www.sicklecellsociety.org

Patient Information

The UK Thalassaemia Society

19 The Broadway, London, N14 6PH

Tel: 020 8882 0011

Website: www.ukts.org

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.

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