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Patient information

The Transition Service for People with Sickle Cell Disease

Haematology Department

This leaflet explains more about the transition service for people with sickle cell disease. If you have any further questions, please speak to a doctor or nurse caring for you.

What is the transition service?

The transition service is a service involved in planning your care and supporting you to move from the children's to the adult hospital.

As you have a chronic condition that will require on-going treatment, it is important that you understand and prepare for the changes you will go through as you grow and what they mean to your care.

The transition team will discuss a number of issues with you. Their aim is to help you understand your condition better and to prepare you for the changeover to adult services.

Who is involved in this process?

The team of doctors and your nurse specialist at Alder Hey Children's hospital will start the process of transition as is mentioned later in this leaflet. You will then come to meet the team of doctors and nurses form the Royal Liverpool University hospital who will lead the care for you as an adult.

Both teams have very close links to each other and they will all help you and your family to work out your healthcare management goals and what services you need in order to reach these goals when moving from children's to adult services.

What exactly will happen to me?

All families are different, and what exactly will happen will depend on how much you as a young person are involved in taking care of your health. We want to make sure that when it is time to move on to the adult hospital, you have developed the right level of understanding and skills for adulthood. We also want to make sure that both you and your family feel confident about making the transition to adult services.

The teams from both hospitals are the link between the children's and the adult hospital and they will work very closely to support you all the way until you are fully settled into the adult hospital.

This process begins with carrying out an initial assessment to understand your needs while you are still in the children's hospital at the age of 12 or 13.

We will use the transition passport document questionnaire, which you can complete either on your own or with the help of either your parents/guardian or the specialist nurse.

The questionnaire will cover subjects like:

- your knowledge and understanding of your condition and treatment plans
- your ability to remember, without your parents' reminders, things like your appointments and taking medicines
- your ability to confidently ask and discuss issues concerning your health with your doctors and nurse
- how you feel about attending the adult hospital when the time comes.

Having sickle cell disease means you have on-going healthcare needs. The teams will also be working with you to support you with strategies to balance your illness with other areas of your life, such as studying, socialising, sports and hospital appointments.

Transition takes time and you will be supported to learn new skills that will help increase your independence and get you ready for adulthood.

Assessment stages

Stage I

When you are 12–13 years old, the team at Alder Hey Children's Hospital will have introduced you and your family to the idea of the transition process.

Stage II

At 14–15 years, the team at Alder Hey Children's Hospital will have helped you increase your understanding of your condition and the whole transition process by having more in-depth discussions and workshops.

Stage III

At 16–17 years, we would expect that all the years of working with you have paid off and you have a considerable degree of independence over your own care. By this stage, we hope that both you and your family feel confident about transferring your care to the adult hospital.

The transition clinic

Between 16 and 17 years old, you will be invited to attend the transition clinic where you and your family will have the opportunity to meet with the adult team, which includes the adult sickle cell consultant and nurse specialist who will be involved in your future care. This clinic takes place in Alder Hey Children's Hospital and the children's sickle cell consultant leads this clinic and makes the necessary introductions.

This clinic gives us the opportunity to discuss and plan how and when you are going to go over to the adult hospital. It is important to plan for this, both so that you are prepared, and so that you have time to say goodbye to all your carers in the children's hospital.

Sometime before your first appointment with the adult doctors, you will be invited to an adolescent transition session, where you will have the opportunity to meet other young people in transition as well as others who have recently transitioned. You will also be able to take a guided tour of the adult hospital and meet the rest of the adult team.

What will happen when I am in the adult hospital?

Transition is a process that will continue over a number of years after you have moved to the adult hospital. Your team will work with you to ensure that your move is smooth and they will support you to adapt to your new environment until you feel that you have settled in.

Please remember to keep the contact details for your team in a safe place for when you need them.

Some of the things that they can help you with are:

- helping you to set and achieve goals
- advising you about services available to you
- talking to other services, including your school, university, or workplace, on your behalf about health issues
- helping to liaise with other clinicians and keep everyone informed about issues you might be concerned about
- providing you and your family with relevant information about the transition process
- helping you learn more about your condition and to become more independent in developing strategies to manage your life as you move into college, university and/or work.

Where do I need to go?

Your adult outpatient clinic is at the Roald Dahl Centre on the ground floor of the Royal Liverpool University hospital.

Feedback

Your feedback is important to us and helps us influence care in the future.

Following your discharge from hospital or attendance at your outpatient appointment you will receive a text asking if you would recommend our service to others. Please take the time to text back, you will not be charged for the text and can opt out at any point. Your co-operation is greatly appreciated.

Haemoglobinopathy / Sickle Cell Team:

Dr D Simcox	**Consultant Haematologist**
Prof CH Toh	**Consultant Haematologist**
Dr V J Martlew	**Consultant Haematologist**
Dr T Dutt	**Consultant Haematologist**
Haematology Specialist Registrar (Rotational Position)	
Francesca Murphy	**Clinical Nurse Specialist**

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All Trust approved information is available on request in alternative formats, including other languages, easy read, large print, audio, Braille, moon and electronically.

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