

Transition from Children's to Adult Services for Young people with Sickle Cell Disorder, Thalassaemia or Rare Inherited Anaemia

i Information for patients, families and
carers

Haematology - Haemoglobinopathy
Coordinating Centre



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What is transition?

‘Transition’ means the process of planning with you for your move from children’s to adult services, and supporting you while you make this change. This process takes place over a number of years, usually starting when you are 11 or 12 years old. Transition is a natural part of growing up, becoming more independent and taking responsibility for your own healthcare.

We use a programme called ‘Ready, Steady, Go, Hello’ to help you to get ready for this transition. This includes the use of questionnaires which you can complete on your own or with the help of your parent or carer, or with your specialist nurse.

You can read more about this programme at the following link:

- www.readysteadygo.net

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

How will we plan for my transition to adult services?

You will plan your transition journey with your specialist nurse at the Children’s Hospital – if you have any questions about transition please ask them any time.

Early on, your nurses and doctors will start helping you to understand more about your condition, and to start taking more personal responsibility for managing your treatment. This might mean learning how to take your medication independently, how to book your hospital appointments, and how to look after your health more generally. As you get older, they will encourage you to start seeing your doctor on your own, for at least part of your clinic appointment.

They will also start to give you information about the adult services, and as time goes on you will be introduced to the healthcare team who will look after you once you move to adult services.

From the age of around 14 years old, you will start to be invited to a 'joint transition clinic'. These are run by your doctor and specialist nurse in the Children's Hospital and the adult team will join them as well to meet you and your family. This is a chance for you to get to know the adult team, to hear about the adult services and ask any questions you might have. You can come to a number of these transition clinics until you feel confident to move over to the adult service.

The adult specialist nurse can also arrange to take you for a look around the adult ward, day unit and clinic area so that you can see it before you move your care to the adult service. Whilst there you can meet some of the staff and ask us questions.

This is what we are here for and we want to make you feel as comfortable as possible.

When will I move on to adult services?

You can move your care over to the adult services at any time between your 16th and 18th birthdays, at a time that is right for you and when you feel comfortable to transfer your care.

Everyone feels ready to move to adult services at different times, and we will make sure you are feeling comfortable and confident to transfer your care to the adult team. You might like to think about when is the right time for you, taking into account timing of your school or college exams, and any other major events going on in your life.

Who will look after me in the adult services?

Most people move on to the adult haemoglobinopathy services at their local hospital.

Meet the team

The team is made up of:

- Lead Haematology Consultant
- There will also be other doctors in clinic who you may see and if you need to come into hospital there will be a team of doctors looking after you.
- Other members within the team you may see include Advanced Care practitioners (ACP) and Physician Associates (PA)
- Your Clinical Nurse Specialists in Adult services. You might see them in clinic, they can help to arrange your medications, and will be there to answer any questions you might have. They will also help support you if you have regular blood transfusions or exchange transfusions and help organise these for you.

Your haemoglobinopathy team may have a psychologist who can provide support to people living with red cell disorders. Please ask your team if you would like to see a psychologist.

Please ask your team if there is a specialist benefits advisor who is there to help and advise on any issues relating to your finances, any benefits you may be entitled to, and any matters related to housing or immigration.

The adult team will give you more detailed information on their services when they meet you in the transition clinic. This will include written information on the clinics, arrangements for having blood tests, and the wards.

Who do I contact if I am unwell?

Before your first appointment in the adult services, please contact your team at the Children's Hospital to arrange your treatment and also if you are unwell. After your first appointment with the adult team, you should get in touch with them instead.

Once you move to adult services, if you need to be seen in hospital because you are unwell, we will do our best to make sure that you can have a parent or family member with you overnight if you would like them to stay with you. This should be the case up until your 25th birthday, but people with additional needs can have someone with them when they are older than this. Please ask if there is a teenage and young adult room where you will find some entertainment options and a quieter space to relax.

You can have a parent or family member come with you to clinic appointments, when you come for blood tests or other investigations, and when you attend for transfusions if this is part of your treatment.

Moving away from home

If you are moving away from home for university, for other training opportunities or for work, this can be a very exciting and busy time. It is important to make sure that you look after your health and get the right support set up in your new area as soon as possible to help you stay healthy and make the most of your new experiences.

We recommend that you:

- 1)** Speak to your specialist team before you go, so that they can provide information about the nearest hospital which can provide you with local care after you move. They will also contact that local team if possible before you leave, to give them some information about you so that they are ready to look after you once you arrive. Depending on how long you are moving for, whether you are going to be back in your home town regularly and your personal preference, you might choose to move all of your care to the new hospital, or continue to have some of your appointments and care in your home town and some in your new location.
- 2)** Before you go, make sure you know who to contact and where to go if you become unwell. Have a copy of your care plan and a list of your regular medication available to show to someone if you need help.
- 3)** If you have regular transfusions, make sure that you know how to arrange your next transfusion (or exchange transfusion) in your new location before you leave – your specialist team will help you with this.
- 4)** Make sure you request a supply of your regular medications before you leave home, in case there is any delay in getting access to these after you move.
- 5)** Register with a GP as soon as you arrive. This is important because they will often be your first contact for general health matters, and to supply of some of your regular medication.

General health issues and questions

As you get older and enter your teenage years, certain issues relating to your health may become more relevant to you. Your doctors and nurses will start to talk to you about the following areas.

Remember that your nurses and doctors are never there to judge you, they just want to support and help you.

Contraception and sexual health

If you are thinking about becoming sexually active, or already are, then it is important to look after your sexual health. Your doctors and nurses at the hospital, or your GP, can help you find the best option for you to prevent unwanted pregnancy and protect you from sexually transmitted infections.

Family planning

Your doctors and nurses will make sure that you have information on the inheritance of your condition, and the chances of any children that you have being affected by the same blood disorder. Once you enter the adult services, they will also need to know if you are planning to have a baby. This is important for many reasons, such as you may need to stop some of the medication you are taking before trying for a baby – this can be the case for both males and females.

Alcohol

If you choose to drink alcohol, it is important that you do this safely. You can help yourself to stay well by drinking smaller amounts, especially not drinking too much in one go, and making sure you drink plenty of non-alcoholic drinks alongside any alcohol, to stay hydrated. Be aware that when you drink alcohol, you can also become cold more easily and can be less aware of becoming unwell or any other risks.

'Recreational' drugs

We can provide you with information on any other drugs and it is important that you tell your healthcare team if you are using any recreational drugs.

Mental health challenges

Teenage and early adult years can be a challenging time for your mental health. If you feel you are struggling with low mood, anxiety or any other mental health difficulties please speak to your healthcare team so that they can support you. They may suggest that you speak with the team psychologist who can offer therapy appointments, or sometimes they might recommend you speak with your GP or might refer you to another service for support.

Support networks, organisations and contacts that can provide further support and guidance

North East and Yorkshire Haemoglobinopathy Coordinating Centre

- www.ney-hcc.co.uk



Sickle Cell Society

54 Station Road, London, NW10 4UA
020 8961 7795
info@sicklecellsociety.org

- www.sicklecellsociety.org



UK Thalassaemia Society

19 The Broadway, Southgate Circus, London, N14 6PH
020 8882 0011

- ukts.org



Congenital Anaemia Network (together we can)

- www.togetherwecan.uk



**Diamond Blackfan Anaemia Syndrome Charity
(DBAS UK)**

0845 094 1548

Contact form on website.

- diamondblackfan.org.uk



If you have any further questions or would like to talk to the team

You can contact the haemoglobinopathy clinical nurse specialists:



To help support your local hospitals visit
sheffieldhospitalscharity.org.uk

Registered Charity No. 1165762



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