

When do I have to leave the Childrens Hospital?

Young people who attend this clinic usually make plans to move up to adult services at some time after they've taken their GCSE exams and before their 19th birthday. If you're planning to go away to college or university it's good to have 'transitioned' before then so you still have the support of family and friends close by. If you'd prefer to make the change as soon as you are 16 we can work with you to make sure you are ready.

I'm going to be 16 next year, who decides what happens next?

Ultimately it's up to you when you move on and depending on where you live, where you move on to, but we know from experience that the move will go most smoothly if you, your parents/carers, the team from the adult hospital and your current paediatric team all work together. Remember it's a time of change for your parents as well as for you.

How will I know when I'm ready to go?

We start talking to young people about transition (the process of moving to adult health care services) a long time before it happens so that there's plenty of time to prepare. We want you to be confident you understand your condition and how to manage it, confident you can talk to adults about what you need (sometimes called self advocacy) and we want you to be good at the everyday things we all have to do to stay well. Things like knowing the importance of a good diet and exercise and how to deal with the stresses of study, exams and /or work.

What about Mum and Dad?

Your parents/carers have spent years becoming knowledgeable about your condition and how it affects you, how to manage it so you stay well and what to do if you are not well. We hope that you are also learning these things – from them, from your team here and from your experiences in everyday life as well as any specialist information you may access either through us or by books or the internet. Mum and Dad won't just be able to 'switch off' when you move to adult care. They will still be concerned to make sure you stay well and look after yourself. They will be welcome at the adult hospital with your agreement, but you will be in charge of your health and expected to do the everyday things like making appointments and collecting prescriptions for yourself

Can I meet the doctors and nurses who will be looking after me when I leave SCH?

Yes, we will arrange a meeting involving you and your parents/carers (with your agreement), the team at SCH and members of the adult team

when we know roughly when you'd like transition to take place. This will be an opportunity to meet and ask questions of the adult team. You should spend a little time beforehand thinking of any anxieties or concerns you have so that these can be addressed. We can help you with this.

Will any staff I know be able to come with me?

A little while before it's time for you to move on we will allocate a member of the Paediatric team to be your transition coordinator. They will be there to help arrange things for you, to help you think about how things might be different at the adult clinic and what responsibilities you will need to be ready to take on. You can contact them if you have any questions or need to change any transition planning arrangements.

What if I don't want to go?

Most people don't like change, but you will find if we plan for your adult life in this setting (health care) it will go hand in hand with growing up in other ways (leaving school, going to college, getting a job). By the time you have to move on, we will make sure you are ready for it and even looking forward to it!

What if I don't like the adult hospital?

There are bound to be things that you like less and things that you like more about the adult hospital compared to SCH. It's important that you let the staff there know if there are things that are making you anxious or unhappy – they may be able to make quite simple changes to help you. You will also still be in touch with your transition coordinator who is there to make the journey as easy as possible. Talk to her about your concerns. She will listen and try to help. She'll also keep your old team at SCH up to date with how you are doing and make sure the new team get to know you as quickly as possible.

What if I become unwell after my last paediatric clinic but before my first proper adult one?

If this happens just contact us at SCH in the normal way – you remain a patient under our care until you have been seen by the adult team at the adult hospital. However we plan for your first adult review to be quite soon after your final paediatric one, so if you have not received an expected appointment or you have missed an appointment it's **really important to arrange another one**. Adult hospitals are much stricter about missed appointments; the onus will be on you to request a new one. Your transition coordinator can help you with this.

Information Leaflet number:
Author/Contact:

758 (15/12/2014)
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Sheffield Children's 
NHS Foundation Trust

Any questions?

Please contact any member of the Haemoglobinopathies Team in the normal way. We are here to help.

Sheila Daley	Haemogloniopathies Nurse Counsellor	2717707
Louise George	Haematology Nurse Specialist	2717329
Vicky Vidler	Haematology Nurse Consultant	2717329
Jenny Welch	Paediatric Haematology Consultant	2717477

TRANSITION FOR YOUNG PEOPLE WITH HAEMOGLOBINOPATHIES (Sickle Cell and Thalassaemia)

For further advice contact:

Main hospital number: 0114 271 7000

Patient Advice & Liaison Team (PALS)

The Children's Hospital

Western Bank

Sheffield

S10 2TH

PALS office: 0114 271 7594

www.sheffieldchildrens.nhs.uk

Our young patients are at the centre of everything we do and all our work is focused on providing them with the best facilities, equipment and experience possible, helping to provide a world-class facility that is positioned at the very forefront of paediatric care.

The
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