

Clinical haematology

Haematology transition

Information for patients, relatives and carers

Introduction

This booklet will explain what transition is, how you will be involved in the process, and what changes happen as you grow older and become an adult. The aim of transition is to make your move to adult healthcare services as smooth as possible.

What does 'transition' mean?

In healthcare, "transition" refers to the process of moving from child and adolescent healthcare services to those for adults. It is a gradual process that gives you and everyone involved time to prepare. Each family takes a different approach to how much you, as a young person, are involved in taking care of your health. As you approach adulthood, we will work with you and your support network to build your confidence and independence in managing your health. It's important to start the transition early. If you're over 14 and your healthcare team hasn't discussed it yet, ask about it at your next appointment.

Why move?

As you grow into a young adult, an adult service will be the best place for you to get the care that is right for you. The staff in children's services are expert in caring for babies, children and teenagers, and the staff in adult services are the experts in caring for young adults, adults and older people.

By the time you are at the end of the transition process, you may feel that you have grown out of children's services and be glad to move on to a more grown-up setting. The thought of moving and leaving the staff that you've known over the years can be difficult. We know from experience that it is a good idea to think of this change as a sign that you are growing up and moving on with your life. You might have felt the same way when you moved from primary to secondary school. Before moving to adult healthcare services, we will offer you plenty of opportunities to talk about transition. We'll also give you information about what might change and the people and places that might be involved in your care as a young adult. When possible, your team will schedule a joint appointment for you to meet the team taking over your care and visit the facilities.

When will I need to move?

The timing of the move to adult healthcare services varies from person to person but for most people it happens soon after your 18th birthday. By this stage, we hope that both you and your family feel confident and ready for your care to be transferred to the adult team.

We want to make the transition as easy as possible for you and your family. To help this happen, clinical nurse specialist/transition co-ordinator is responsible for organising your transition. They will ensure that you are supported throughout the process and have everything you need to feel ready to move to adult services. They work closely with the clinical nurse specialist in the adult team.

What happens in the adult services clinic?

Now you are older, we will offer you some time alone with your doctor or nurse and meet the doctors and nurses from the adult services. You'll be able to talk about the things that matter most to you, to practise asking your own questions and to get to know your doctor or nurse better.

You could start by spending just a few minutes on your own either at the beginning or the end of your appointment. If your team does not suggest this, let them know this is something you would like and they will happily arrange it for you. We will give you the opportunity to talk about how your health needs may impact your future including employment, independent living, sexuality and relationships.

What can I do to get ready to move on to adult healthcare services?

Your parents/carers have played an important role in looking after your health and will be able to give you lots of helpful advice. They will have plenty of experience of things such as taking you to the hospital, making appointments, asking questions and making sure you get your medicines or treatments. It is a good idea for you and your parents/carers to talk about how moving to adult healthcare services makes you feel. You should make plans with them about how you can practise getting involved in looking after your health and taking responsibility.

As you get older your parents/carers will still be able to support you and be involved in your healthcare. It will be up to you to decide how much you would like your them to be involved. If you know any other young people that have already finished their transition, it might be useful to ask them for tips on how to get ready and questions about the adult healthcare service. You will also get a chance to visit the clinics and wards you will attend after moving over to the adult services.

It might be helpful for you to practise doing these things to help prepare you for adult care:

- Practise asking and answering questions during clinic appointments so you can learn about your health and treatment
- Remember to take your medicines and learning what they are called, what they are for, how much to take, when to take them and how to get more
- Practise arranging appointments with your consultant, family doctor (GP), clinical nurse specialist and learn how to cancel if you need to
- Keep important phone numbers and appointment dates in your mobile phone, calendar or diary

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- Learn about any changes to your condition that mean you need to get urgent help
 - Find out who to contact in an emergency

Confidentiality

What you say to a healthcare professional is private and stays private. The exceptions to this are if you and/or other people might be at risk of harm. If this is the case, the member of the team will discuss with you what parts of the information might need to be shared, who with, why it might be shared and how. They do not have to tell your parents what you have said in an appointment and would only do this with your permission. If there is something you are finding difficult to share with your parents, they can help you with this if you want. As we work as a team, individual staff might need to discuss your issues with other team members. If you don't want information to be shared, please let one of the team know.

Changes after your 16th birthday

Your 16th birthday may seem a long way off but there are important legal changes relating to your health that happen then. We're telling you about them now so that you have lots of time to get ready.

Consent: After your 16th birthday, you might be the one asked to decide about your own treatments or operations. This will sometimes involve signing a consent form. There's no need to do this on your own – you can still discuss your options with your parents/carers, doctors or nurses. There are different rules about consent if the doctors think someone can't understand information well enough to make a decision on their own.

Hospital communications: Once you are 16 years old, communications about your health should be addressed to you. This includes appointment letters, discharge summaries, clinic letters and test results. You can decide who can receive copies of letters or look at your medical notes after this age.

Appointments: We encourage you to make appointments for yourself after you are 16. Your parents/carers will only be able to make, cancel or change your appointments if you have given the hospital permission for them to do so. Booking and keeping track of appointments is an important skill to learn. You can ask your parents/carers how they make your appointments and keep track of dates. They might be able to help while you learn to do it for yourself.

Benefits: You might be receiving a Disability Living Allowance (DLA) payment to help with any additional costs. After your 16th birthday you will need to be reassessed to see if you qualify for a different payment called a Personal Independence Payment (PIP). The Department for Work and Pensions will contact you before your 16th birthday to explain how to claim for PIP. Details are available on the Contact for families with disabled children website (see page 5) or from your local Citizens Advice Bureau.

Ready, Steady, Go, Hello!

We use the Ready, Steady, Go, programme to help prepare and support children, young people and their parents/carers as they move to adult healthcare services. The aim of the programme is to help young people to take more control of their lives and manage their own health care.

Stage 1: *Ready* this will happen between the ages of 14 and 15 years. We introduce you and your family to the idea of transition and what it might mean for you.

Stage 2: *Steady* from 15 to 16 years, we help you to understand your treatment and condition, what you can do to help yourself, and how transition works. We do this by talking about it in more detail.

Stage 3: *Go* At 17 to 18 years, we hope that you understand treatment and condition, what you can do to help yourself now and in the future, and where to find help if you need it.

We will be able to give you support for moving on and getting ready for adult services by helping you with some of things from page three that you might have practiced already. We'll also give you information about your condition or illness, how it might affect your education and career plans, and how to have a healthy lifestyle (including exercise, diet, smoking and sex).

After moving to adult healthcare services it can be difficult to leave behind the people you have got to know in the children's service. It is important to know that you can stay in touch with the children's team, but your new adult team will be your first point of contact in all matters related to your treatment and health. Transition will be slightly different for each person. By talking about transition early and leaving plenty of time for discussions and questions, we hope that when the time comes for you to move to adult healthcare services you will feel fully prepared. If you have any questions after reading this leaflet, please speak to the team caring for you.

Can I choose where I move to?

Part of the transition process should be helping you to look at where your ongoing healthcare needs can best be met and how this will fit in with your future plans. Your team will be able to give you information to help you make the best decision. If there is a choice of places, it is a good idea to visit all of them and then decide which is best for you.

The team

- Dr Kirstin Lund, consultant paediatric haematologist
- Dr Steven Okoli, consultant adult haematologist
- Dr Mamta Sohal, consultant adult haematologist
- Dr Asad Luqmani, consultant adult haematologist
- Miss Catherine Mkandawire, matron (Haemoglobinopathies and apheresis children and young people)

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- Miss Kajal Rai, clinical nurse specialist (Haemoglobinopathies children and young people)
 - Ms Caroline Cheo, clinical nurse specialist, (Adult haemoglobinopathies and children and young people)
 - Ms Afoke Arigbe, clinical nurse specialist, (Adult haemoglobinopathies)
 - Ms Nancy Huntley, clinical nurse specialist (Apheresis children and young people)
 - Miss Ristell Fernandes, clinical nurse specialist (Apheresis children and young people)
 - Mr Renzo Tiong, clinical nurse specialist (Apheresis children and young people)

Contact details

Haemoglobinopathies admin team: 0203 312 6157

Haemoglobinopathies clinical nurse specialist team – Children and young people (09.00 to 17.00): 07795651153, imperial.paediatrichaemoglobinopathies@nhs.net

Haemoglobinopathies clinical nurse specialist team – adults (09.00 to 17.00):
07776227760

Renal and haematology triage unit (RHTU) (24/7 access to urgent care for haematology patients): 02033117755

Address: Imperial College Healthcare NHS Trust, St Mary's Hospital, Praed Street, London W2 1NY

Further information and support

<https://www.imperial.nhs.uk/our-services/adolescent-and-young-adult-healthcare---11to25>
<https://www.readysteadygo.net/>

If you live in the following areas, further support is available via your local Sickle Cell & Thalassaemia Centre:

Brent: 020 8453 2050 / 2052

Ealing: 020 8967 5643

Hammersmith, Fulham and Westminster: 020 7266 8892

Sickle cell Society

020 8961 7795

info@sicklecellsociety.org

www.sicklecellsociety.org

Sickle Cell Information Centre

www.scinfo.org

Thalassaemia Society

thalassaemia@cytanet.com.cy

www.thalassaemia.org.cy

Sickle Cell and Young Stroke Survivors (SCYSS)

0800 084 2809 or 020 7277 2777

info@scyss.org

scyss.org

Contact

The charity for families with disabled children

www.contact.org.uk/

The Hope Project Scotland

07756 266 691

thehopeprojectscotland.org.uk

Citizens Advice Bureau

www.citizensadvice.org.uk/

The Care Information Exchange (CIE)

CIE gives secure online access to information from the hospital such as test results, appointments and letters. Young people and their parents can also add things like symptoms the young person is experiencing to give a more complete record. To register and access the record QR code below to download the application.

Everyone registering will need to complete a form, show proof of identification, and have an email address. The email address will be the login name, and the address for notifications when something new is added to the record. Go to www.careinformationexchange-nwl.nhs.uk/ or scan this QR code with your phone camera to find out more and register:



How do I make a comment about my visit?

We aim to provide the best possible service and staff will be happy to answer any of the questions you may have. If you have any **suggestions** or **comments** about your visit, please either speak to a member of staff or contact the patient advice and liaison service (**PALS**) on **020 3312 7777** (10.00 – 16.00, Monday to Friday). You can also email PALS at imperial.pals@nhs.net The PALS team will listen to your concerns, suggestions or queries and is often able to help solve problems on your behalf.

Alternatively, you may wish to complain by contacting our complaints department:

Complaints department, fourth floor, Salton House, St Mary's Hospital, Praed Street
London W2 1NY

Email: ICHC-tr.Complaints@nhs.net

Telephone: **020 3312 1337 / 1349**

Alternative formats

This leaflet can be provided on request in large print or easy read, as a sound recording, in Braille or in alternative languages. Please email the communications team:
imperial.communications@nhs.net

Wi-fi

Wi-fi is available at our Trust. For more information visit our website: www.imperial.nhs.uk

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