

Patient information

Transition to Adult Care for Bleeding Disorders

Haematology Liverpool

This leaflet explains how your care is transitioned from Paediatrics to Liverpool University Hospitals Foundation Trust. If you have any further questions, please speak to the Haemophilia team.

What is transition?

When children become adults, they normally make decisions for themselves so they can be more independent. Children's health and care needs change as they grow up and the adult service becomes better suited to them. Transition to adult care (transition) is the name given to the process of moving from children's to adult care.

Transition is an important journey. The Haemophilia teams at Alder Hey and at the Royal Liverpool Hospital will work with you and your family to ensure that you get the support you need. We will ensure that you and your family understand what is happening, feel confident and in control.

Why is transition needed?

Transition is important to ensure that services are appropriate for your needs and age. If we didn't have transition to adult care adults would be on the same wards as children which would cause multiple issues with safety, care, and logistics.

What will happen?

Young people and their families often need guidance and encouragement but shouldn't feel rushed or unsupported. Transition is a gradual process. Alder Hey will start this process, and we will then carry this on, starting with your referral.

1. **Referral to adult services.** The Liverpool University Foundation Hospitals Trust (LUFHT) haemophilia team will receive a referral from Alder Hey around the age of 14 so we can begin to see your clinic letters and build up a clinical picture of you.
2. **Joint reviews in Alder Hey.** You will be invited to attend a Transition clinic, led by your team in Alder Hey, but with members of the adult team also present. This will allow you to get to know the professionals who will be taking over your care.

3. **Joint reviews in Royal Liverpool.** You will be invited to attend a Transition clinic led by the Haemophilia team in the Royal, joined by members of the team from Alder Hey. This will help you get used to the new team and hospital, with support from your team in Alder Hey.
4. **Planning emergency care.** Once you have moved into adult services, you will need to know what to do and who to call when you are unwell. We will make sure your GP has the necessary information to support you. Once you have moved into adult services, you will not be taken to Alder Hey if an ambulance is called or you need to come into hospital. We will make sure you know which hospital you are likely to be taken to and that they have the necessary information to support you.
5. **Moving to adult services.** Eventually you will be ready to attend the adult clinic or be admitted to the adult hospital ward. We hope that, with our support, you will feel confident and ready to make this decision. Most young people are ready to move into adult services when they are 16 or 17. This means children's services can provide support to adult services if necessary.
6. **Completing transition.** Finally, usually before your 19th birthday, we hope you will feel confident and well supported in adult services and we will be able to discharge you from children's services.

How will this affect you?

Once you are under the care of the adult Haemophilia team, all contact from the hospital will be directly to you. We cannot send letters to or talk on the phone with your parent or guardian without your permission. We will need to make sure that the telephone number we have on record is yours, and that your address is correct.

You will receive text message reminders to your phone for all clinic appointments. If we need to call you, the number will likely show up as a Private or Unknown Number. It is important that you answer our calls so that we can offer you the best care. It is very important that you let us know if you can't attend an appointment. In most cases, we will need to see you at least once in every six months. If you can't attend, please call us to rearrange the appointment. It is better to call the Haemophilia Team directly, rather than the hospital appointments line.

If you are receiving home delivery of treatment, we will take over this. You will need to be able to take responsibility for accepting deliveries of your treatments and answering calls from your home delivery company. You can give them permission to speak with a parent or guardian, if you would like. The home delivery company may well be the same as used by Alder Hey. We will talk to you about this in clinic.

All patients receiving home delivery will need to sign a Home Delivery Agreement with us. This means that we can provide you with the best care. It includes making sure that you attend your outpatient clinics and record all treatments using Haemtrack.

We will arrange for your Haemtrack account to be transferred to us from Alder Hey. Your account details (login, password) will remain the same, but we will then be able to review your records.

We will arrange to transfer your registration to us on the National Haemophilia Database. This will mean that we will be responsible for your care, and you will also receive an updated Bleeding Disorders Alert Card, with our centre details on.

How do I contact the Haemophilia team?

Please call: 0151 706 3397 (working hours: 8.30am to 5pm)

You can speak to or leave a message for any of the haemophilia team on this number, including:

Jayne Keaney (Clinical Nurse Specialist)
Rhian Parry (Clinical Nurse Specialist)
Reena George (Clinical Nurse Specialist)
Alfie McBrien (Haemophilia Physiotherapist)
Dr Cathy Farrelly (Consultant Haematologist)

Out of hours service: Please contact switchboard on 0151 706 2000 to contact the On Call Haematology Registrar or Consultant oncall for Haemophilia.

Further information

The Haemophilia Society: <https://haemophilia.org.uk/>

NHS Choices:

NHS Choices provides online information and guidance on all aspects of health and healthcare, to help you make decisions about your health.

Web: www.nhs.uk

NHS 111:

You can call 111 when you need medical help fast but it's not a 999 emergency.

NHS 111 is available 24 hours a day, 365 days a year.

Calls are free from landlines and mobile phones.

Tel: 111

Author: Haematology Liverpool

Review date: December 2027

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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