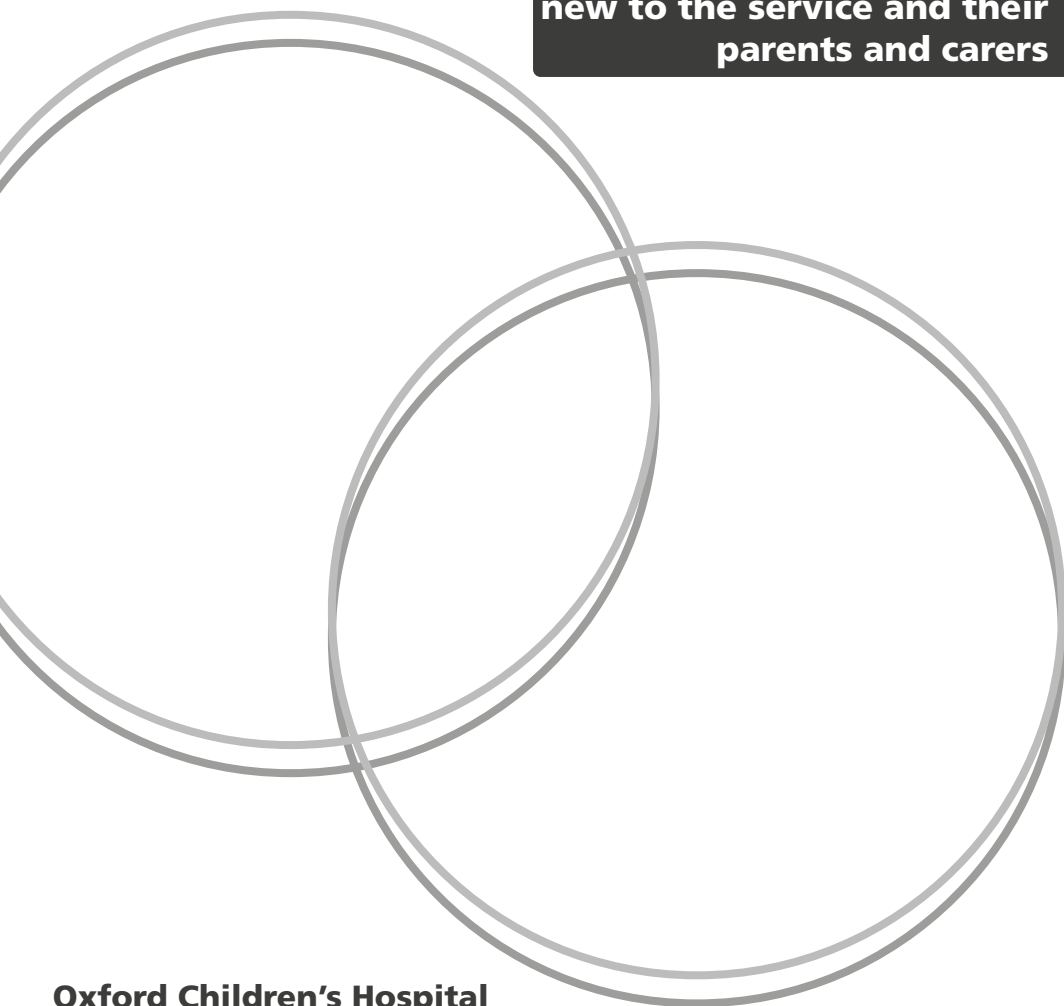


Welcome to the Paediatric Haemostasis Service

**Information for children
new to the service and their
parents and carers**



What is this leaflet for?

You have been given this leaflet to explain the care your child can expect from the Paediatric Haemostasis Service and how we can help your child.

Who are we?

The Paediatric Haemostasis Service cares for young people with haemophilia and other bleeding disorders who live in the Thames Valley region and beyond. We are here to support you and your child and answer any questions you might have.

Our team is made up of:

- consultant paediatric haematologists – who oversee your child's care
- advanced clinical practitioners – who help support you and your child with your day to day care
- research nurse – who will support you and your child if your child is on a clinical trial
- a physiotherapist – who will help your child to keep their joints and muscles healthy
- a psychologist – who will support you and your child if you have any worries or concerns
- a secretary – who will make appointments for your child and send your child's clinic letters.

Please visit our website for further information

www.ouh.nhs.uk/kamrans/haemophilia/

Regular appointments

Your child will have an appointment with the Paediatric Haemostasis clinic at least once a year, depending on their age and diagnosis.

At their appointment they will be seen by a nurse or doctor and, if needed, a physiotherapist. The clinics are on Tuesday afternoons and Thursday mornings in the Children's Outpatient Department, on the lower ground 1 (LG1) of the Children's Hospital. If you would like to see a psychologist a referral can be made.

Shared care

Your local hospital will still be the place you should take your child if there is an emergency (such as if they have injured their head), as they will need to be checked urgently. This is called 'shared care'.

Your child's shared care hospital will arrange for them to come to the Children's Ward or A&E immediately, if they need to. They will be copied in on all your child's hospital letters so they are kept up to date with what is going on with your child's care.

My child's shared care ward, hospital:

Contact phone number:

It is important that you:

- Contact the Paediatric Haemostasis Service if your child has a bleed, as we will be able to give you advice immediately and may need to see them
- Keep a record of your child's treatment and any bleeds using Haemtrack (if they are on regular factor prophylaxis)
- Contact us if your child has any surgery or procedures planned
- If surgery is required, it should be planned for early in the week, and the relevant surgical team should contact the Paediatric Haemostasis Service. We cannot support private procedures
- Carry your child's bleeding card with you at all times and contact us for a replacement if you lose it
- Contact us if you need to change or cancel an appointment. If possible, please give us at least two weeks' notice, so we can give the appointment to someone else

How to contact us

Paediatric Haemostasis Specialist Nurses

Tel: 01865 226 562

(9.00am to 5.00pm, Monday to Friday)

For appointments and enquiries:

Paediatric Haemostasis Secretary

Tel: 01865 234 212

Email: paediatric.haemophiliaclinic@ouh.nhs.uk (non-urgent only)

(9.00am to 4.00pm, Monday to Friday)

For emergency advice or treatment outside office hours, at weekends and on Bank holidays, telephone the Oxford University Hospitals switchboard.

Tel: 0300 304 7777

Ask to speak to the 'on-call Specialist Registrar for Haematology'.

The Specialist Registrar may give you advice over the telephone or, if your child needs treatment, they may ask them to come in to Kamran's Ward, which is on Level 0 of the Children's Hospital at the John Radcliffe Hospital.

Kamran's ward Tel: 01865 234068/9

Clinical trials

Clinical research allows us to constantly improve the care given to our patients. This might include trials of new agents, new procedures or devices, or even new ways of using existing treatments. At the Paediatric Haemostasis Service, we are part of many clinical research studies. If there is a clinical trial available which relates to your child's bleeding disorder, we will let you know about it and any options available to you.

Moving home or starting at a new school?

If your child moves to another area, you will need to register them with the local doctor's surgery (general practitioner or GP). You will need to make sure the company that delivers your child's factor has your new address.

If your child is starting at a new school, please speak to the specialist nurses about them visiting your child's school or sending the school information, so that your child's teachers and staff know about their condition.

If you are moving further away and would like to transfer your child's care to another Paediatric Haemostasis Service closer to you, we can arrange this.

Self-infusion

If your child has a bleeding disorder, has regular factor prophylaxis and is interested in learning how to give them self factor, we can discuss this with you in clinic.

Moving to adult services?

Transition is the process of preparing, planning and moving from the Paediatric Haemostasis Service to the Adult Haemophilia and Thrombosis Centre.

We use the 'Ready...Steady...Go' programme, which is designed to help your child get the knowledge and skills to manage their condition by them self, as they become an adult. Your child will be supported by the doctors and nurses throughout this time.

The Paediatric and Adult Haemostasis Services are part of the Oxford Haemophilia and Thrombosis Comprehensive Care Centre. This means your child can access all the care they may need for their bleeding disorder in one place.

Dental care

If you have been diagnosed with a bleeding disorder we advise you see a dentist locally every six months as a preventative measure rather than an emergency. It is very important that you receive regular dental care.

Dental treatment

The majority of your treatment will not cause significant bleeding and may be carried out by a general dental practitioner (dentist) or within the public dental service. However, if extractions are needed you should contact us for advice, and you may require a referral to the East Oxford Dental Service.

If you have any questions about your dental treatment contact the Paediatric Haemostasis Service.

Vaccinations

If you have been diagnosed with a bleeding disorder, all vaccinations should be administered subcutaneously - that is just under the skin rather than deep in the muscle. You can obtain all your vaccinations via your GP practice nurse or school nurse.

Advice regarding administration of subcutaneous injections is given to all GP practice nurses in Chapter 4 of the green book.

If you have any questions regarding vaccinations, contact the Paediatric Haemostasis Service.

Additional support

If you or your child need any additional support, such as an interpreter or information in another way or language, help with finding out about benefits, ways to give feedback (including how to make a complaint), or spiritual support, we can give you and your child advice about who you can talk to.

We also carry out a patient survey of your clinic experience and an annual paediatric haemostasis survey. Please let us know if you or your child would like to complete the survey and help improve our service.

Useful websites

The Haemophilia Society

www.haemophilia.org.uk

This is the only national, independent charity for all people affected by bleeding disorders. The website has useful information for patients, families and schools. They organise weekends away for people who have just been diagnosed and inhibitor patients (and their families), as well as many other events, some which our patients and their families have been involved in and found helpful.

World Federation of Hemophilia

www.wfh.org

This website has useful patient information on a wide range of bleeding disorders. It is useful if you want to go on holiday, as it has details of haemophilia centres all over the world.

Further information

If you would like an interpreter, please speak to the department where you are being seen.

Please also tell them if you would like this information in another format, such as:

- Easy Read
- large print
- braille
- audio
- electronic
- another language.

We have tried to make the information in this leaflet meet your needs. If it does not meet your individual needs or situation, please speak to your healthcare team. They are happy to help.

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Oxford University Hospitals NHS Foundation Trust
www.ouh.nhs.uk/information



Making a difference across our hospitals

charity@ouh.nhs.uk | 01865 743 444 | hospitalcharity.co.uk

OXFORD HOSPITALS CHARITY (REGISTERED CHARITY NUMBER 1175809)

