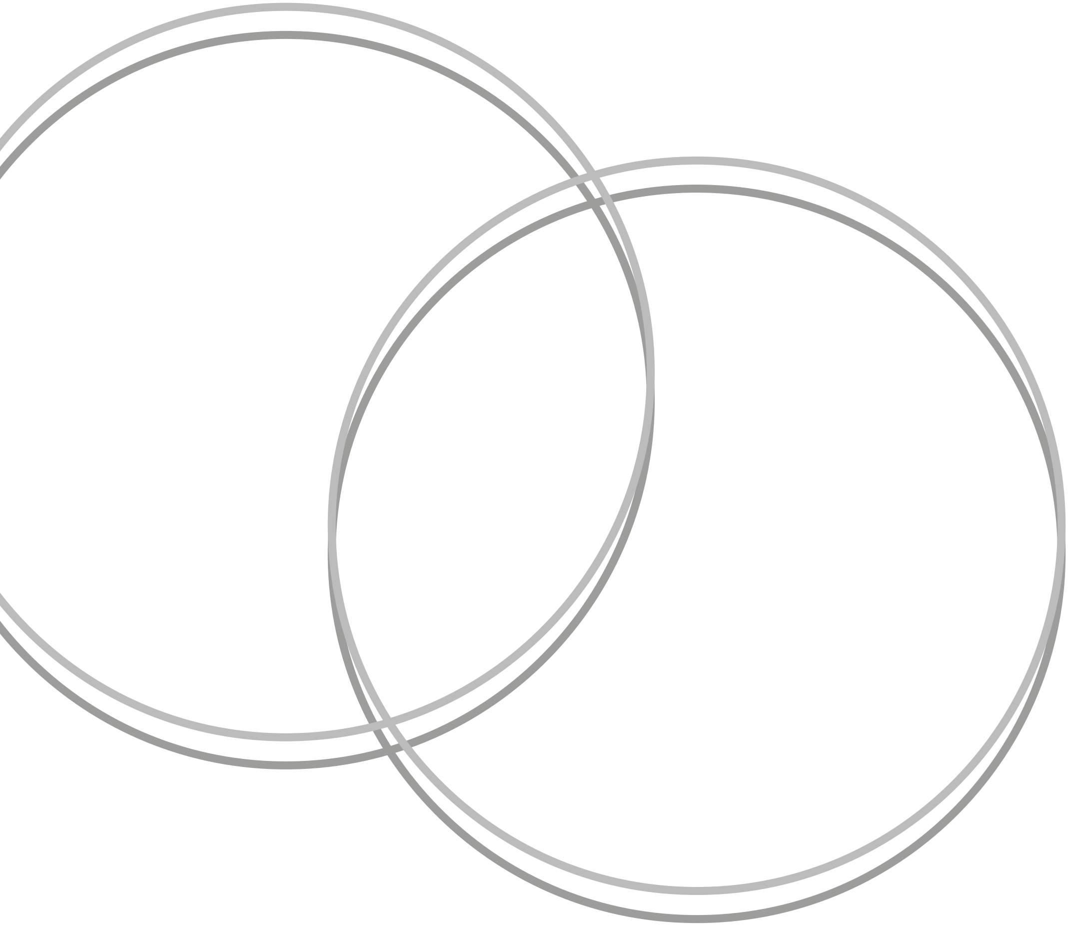
Oxford University Hospitals
NHS Foundation Trust

Welcome to the Paediatric Haemophilia and Bleeding Disorders Service

Information for parents of children new to the service



What is this leaflet for?

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

Who are we?

The Oxford Paediatric Haemophilia and Bleeding Disorders 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
- specialist nurse 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/default.aspx

Regular appointments

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

At their appointment they will be seen by a nurse, 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.

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 Haemophilia and Bleeding Disorders team 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
- 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 Haemophilia and Bleeding Disorder Specialist Nurses

Tel: 01865 226 562

(9.00am to 5.00pm, Monday to Friday)

For appointments and enquiries:

Paediatric Haemophilia and Bleeding Disorders 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 Children's Haemophilia Centre, 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 Haemophilia Centre closer to you, we can arrange this.

Peer support

If your child is pre-school age, you will be invited to **Prickles Club**. The aim of Prickles club is to provide an opportunity for families caring for pre-school children with haemophilia and other bleeding disorders to meet other families and to share their personal experiences in an informal environment over a coffee.

If your child has haemophilia, has regular factor prophylaxis and is interested in learning how to give them self factor, we can discuss this with you. We organise a self-infusion day, which is a fun activity day where your child can meet other boys of a similar age to share their experiences and practise giving them self factor. Your child will be able to practise intravenous access on a dummy arm, on willing volunteers or on them self!

Moving to adult services?

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

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 Haemophilia 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.

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 our service each year. 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.

Author: Paediatric Haemophilia Team
June 2021
Review: June 2024
Oxford University Hospitals NHS Foundation Trust
www.ouh.nhs.uk/information

Leaflet reference number: OMI 75114