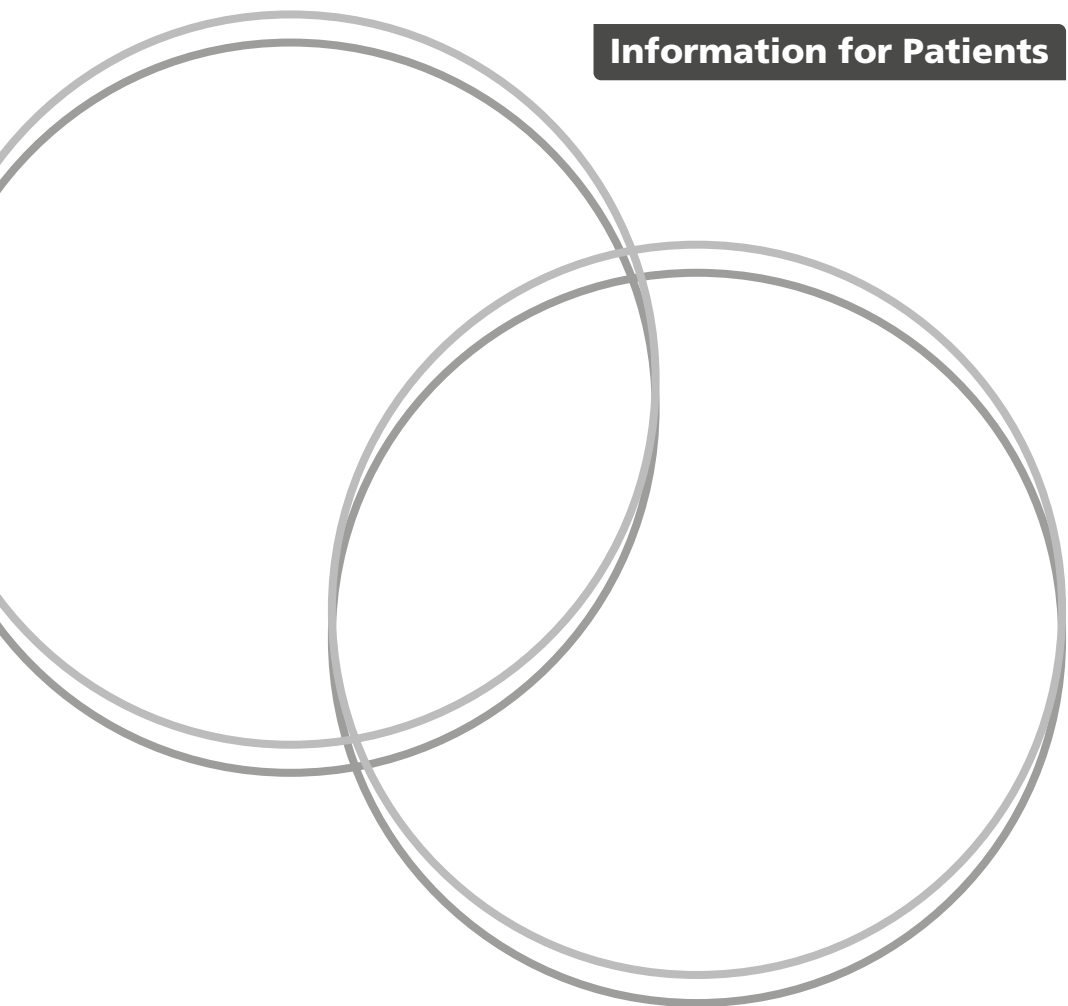




Oxford University Hospitals
NHS Foundation Trust

Welcome to the Adult Haemophilia Comprehensive Care Centre

Information for Patients



This leaflet contains important information about the Adult Haemophilia Comprehensive Care Centre and the services it provides.

We provide care for people with:

- haemophilia A – factor 8 (VIII) deficiency
- haemophilia B – factor 9 (IX) deficiency
- von Willebrand disease
- other factor deficiencies (Fibrinogen, FV, FVII, FX, FXI, FXIII, combined FV and FVIII)
- platelet disorders
- other rare bleeding disorders, including acquired haemophilia.

We can also help you to move over from Children's haemophilia care to the Adult service.

The aim of the service is to make sure you have appropriate treatment of your medical condition and are supported with your physical and mental health, social needs, and managing your life-long condition.

If you have haemophilia or another bleeding disorder, you will not bleed faster than normal, you will bleed for longer. This bleeding may be spontaneous (for no apparent reason) or as a result of an injury or following surgery. The most common types of bleeds are:

- bleeding in the joints
- muscle bleeds
- nosebleeds, gum bleeding, heavy periods and bruising
- bleeding following surgery or minor procedures.

Routine care

If you have a **severe bleeding disorder** you will need to come to the centre every six months for a clinic appointment, to be seen by a nurse, doctor and physiotherapist.

During these appointments you will have an overall review of your health, activity levels and your factor treatment. We may also take blood samples to measure your factor levels.

If you have a **moderate to mild bleeding disorder** you will either come for a clinic appointment every 6 or 12 months, or may be reviewed once a year over the telephone by a Specialist Haemophilia Nurse.

We also can refer you to other specialists, including dental care, orthopaedics (bone care), hepatology (liver specialists), infectious disease specialists, obstetrics and gynaecology (for pregnancy and women's health issues) and geneticists (for genetic counselling).

We can provide both you and your family or carers with education and support, both at the centre and over the telephone. We can also carry out home visits when needed, where a nurse, doctor or physiotherapist will assess you at home.

Inpatient Care

If you need to be admitted to hospital for treatment, we will always try to accommodate you at the Churchill Hospital. However, you may be put on another ward at the Churchill Hospital, John Radcliffe Hospital or the Nuffield Orthopaedic Centre that is more appropriate for your care. If you are on another ward, your Haemophilia Team will still come to see you each day to review your treatment.

Clinics

If you are new to the Haemophilia service, or are pregnant, you will be invited to a Thursday morning clinic, which is held between 9.30am and 12.30pm.

The Adult Haemophilia and other bleeding disorder **follow-up** clinics are held on a Tuesday and Wednesday morning, between 9.30am and 12.30pm.

The **Joint Injection clinic** is held on the first Wednesday of every month between 9.30am and 12.30pm. You will see a specialist rheumatologist doctor and a physiotherapist.

The **telephone clinics** are run by Specialist Haemophilia Nurses for mild bleeding disorders and are held twice weekly, both mornings and afternoons.

Your appointments will be made in advance and sent to you. A reminder letter or text message will be sent to you closer to your appointment date. If you are not able to come for your clinic appointment, please call the reception desk at the Haemophilia Centre in advance, to reschedule your appointment. We can then offer the appointment slot to another patient.

If you fail to come for your clinic appointment, a Haemophilia Specialist Nurse will contact you to discuss and support you with arranging a new follow-up appointment.

If you do not attend three appointments in a row, without letting us know, you will be discharged back to the care of your GP. You will still have access to emergency treatment.

Treatment

We offer a variety of treatment options at the centre. These will be discussed and decided upon with you and the clinical team providing your care.

How you can help

To help us provide you with the best care, we would like you to help us by:

- keeping a record on Haemtrack of any bleeds you have and the factor treatment used. Contact the centre for further advice or support.
- carrying a bleeding card with you at all times and contacting us for a replacement if it is lost
- keeping us informed of any future operations or invasive procedures (such as dental work, endoscopy investigations, joint injections), so we can provide you with the appropriate support.

You may need factor replacement or treatment prior to the procedure. We would greatly appreciate it if you could let us know in advance, to give us plenty of time to prepare a plan for you for your operation or procedure. This will also help prevent your operation or procedure from being delayed.

Physical activity

It is important to carry out some gentle physical activity, in addition to the exercises provided by your physiotherapist.

Aim to complete 150 minutes of 'moderate' exercise a week. This can be broken up into to 30 minutes of moderate aerobic exercise 5 times a week, such as walking or cycling on a stationary exercise bike. 'Moderate' exercise refers to activity which raises your heart rate, making you breathe faster and feel warmer.

You should be working to a level where you are still able to maintain a conversation.

Follow-up

When you leave hospital will be offered a referral to Outpatient Physiotherapy by your physiotherapist, to continue your rehabilitation.

If you have any questions about your exercises or referral, please contact the Specialist Surgical Physiotherapist.

Telephone: **01865 235 391**
(8.00am to 4.00pm, Monday to Friday)

Going to college or university?

If you are moving away to go to college or university, we will continue to provide routine follow-up care for you during the holidays. However, you may want to share your care and register with a Haemophilia Centre closer to where you will be staying. You will also need to temporarily register with a local or campus GP service.

When you tell us of your move, we can make sure you have the contact details of the local Haemophilia Centre and they are aware, should you require emergency treatment during term time.

What to do if you have a bleed or an injury

Please contact us if you have a bleed. Treat yourself promptly using your 'on demand' factor dose. This will help to prevent long-term damage.

If you do not have treatment with you, or are unable to treat yourself with factor, you must contact the Haemophilia Specialist Nurses or doctors immediately. We will need to assess the injury or bleed over the telephone and decide whether you need to come to the centre for factor treatment or go to your local hospital.

Outside of working hours and at the weekend, you must call the hospital switchboard and ask for the 'Haematology Specialist Registrar on-call' for advice.

If you are out of the area and not able to get to the Haemophilia Centre, Churchill Hospital or Emergency Department at the John Radcliffe Hospital, you will need to go to your nearest Emergency Department for assessment and treatment. If you are able to, let us know you are receiving treatment at a different hospital and we can contact the doctors who are looking after you to offer advice and support.

Remember PRICE:

- **Protection**

Protect or support the injured joint or muscle. Using a sling, splint or crutches may help. If you have a bleed in your knee or ankle, you should use crutches to keep the weight off that leg. You can speak to the physiotherapist at the centre for further advice.

- **Rest**

The affected area should be rested completely. This allows the swelling to go down (which usually happens within 48 hours) and prevents further bleeding. The injured area should not be forced into a position, but should be in the most comfortable position possible.

- **Ice**

This helps to reduce swelling, prevent further bleeding and eases pain. Apply something cold; frozen peas will do or crushed ice wrapped in a cloth. You should apply this for 10 minutes on, then 10 minutes off, several times a day (remember ice can burn the skin, so be careful not to leave it on too long or let it touch your bare skin).

- **Compression**

Increased swelling may give you more pain. Compression can help to reduce swelling and therefore reduces pain. You may benefit from wearing an elasticated bandage over your injured limb.

You can be shown how to fit this correctly by a physiotherapist or nurse at the Haemophilia Centre. Try not to allow wrinkles in the bandage, as this may damage your skin or cause uneven compression pressures. Remove the bandage at night, as you don't need to wear it when resting.

- **Elevation**

Raising up the injured area will help to reduce swelling and relieve pain, by encouraging blood to flow away from the injured area. The injured area should be raised above the level of your heart frequently, for 20 minutes at a time.

How to contact us

Adult Haemophilia Centre

(9.00am to 5.00pm, Monday to Friday)

Reception: **01865 225 316**
(for appointments and enquiries)

Nurses: **01865 225 309** or **01865 225 308**
(for advice or treatment)

Mobile: **07776 135 752**
(for advice or treatment during office hours only)

Email: haemophilia.reception@ouh.nhs.uk (Reception desk)
oxford.haemophiliaclinic@ouh.nhs.uk (Nurses)
(emails for non-urgent use only)

Out of hours: Emergency advice or treatment

(outside office hours, on weekends or public holidays)

Tel: **0300 304 7777**

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

Out of hours or weekend treatment is provided by the **Triage Ward** or **Haematology Ward** at the Churchill Hospital.

Triage Ward

Tel: 01865 572 192

(8.00am to 8.00pm, 7 days a week)

Triage Assessment, Level 1, Cancer and Haematology Centre

Haematology Ward

Tel: **01865 235 048** or **01865 235 049**

Haematology Ward, Level 1, Cancer and Haematology Centre

The ward is open to visitors at any time. The electronic doors to the ward close between 9.00pm and 7.00am. Please use the intercom outside the door for access during this time.

Useful websites

The Adult Haemophilia Comprehensive Care Centre webpage, on the Oxford University Hospitals website. This link provides information on and links to a range of topics related to your care. These include treatment, travel, healthy living, local support groups, carers and benefits advice and staff contact information.

www.ouh.nhs.uk/haematology/services/haemophilia

Our patient guide answers practical questions about attending hospital as an inpatient, outpatient or visitor.

www.ouh.nhs.uk/patient-guide

The Haemophilia Society is the only national, independent charity for all people affected by bleeding disorders. They offer information about:

- choosing a career
- benefits you might be entitled to
- travel
- volunteering, campaigning and fundraising.

www.haemophilia.org

The World Federation of Haemophilia offers additional information and support, such as:

- Citizen Affiliate – a global haemophilia community, with information on the latest research, news and up-coming events.
- Young Voices – a series of articles specifically designed for young adults with a bleeding disorder.

www.wfh.org

The NHS website provides helpful information and support, such as:

- an A-Z of health conditions and treatment
- Living Well – over 100 topics on healthy living
- care and support topics – guides to social care
- health news and services near you.

www.nhs.uk

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

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