

## Patient information

### Welcome to the Haemophilia Comprehensive Care Centre

#### Haematology Liverpool

This leaflet contains important information about the 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 aim to provide you with appropriate treatment for your medical condition and to support you 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, but you will bleed for longer. This bleeding may be spontaneous (for no apparent reason) or because of an injury or 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 are diagnosed with a bleeding disorder, you will remain under our care life-long.

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

If you have a **mild to moderate bleeding disorder**, you will need to come for a clinic appointment once every six or twelve months. These appointments may take place in person in the outpatients department, or you may be offered a telephone appointment with a doctor or haemophilia specialist nurse.

We can also refer you to other specialists, such as orthopaedics (bone and joint care), hepatology (liver specialists), infectious disease specialists, obstetrics and gynaecology (for pregnancy and women's health issues), geneticists (for genetic counselling) and to the special care dentistry team in the Liverpool Dental Hospital.

## Clinics

If you are new to our service, or have a **mild to moderate bleeding disorder**, you will be invited to a clinic on a Wednesday morning. This is held in Outpatients 1, Ground Floor, Royal Liverpool Hospital between 9.00am and 12.30pm.

If you have a **severe bleeding disorder** and / or require regular treatment at home to prevent bleeding (prophylaxis) you will be invited to a clinic on a Friday morning. This is held in Outpatients 3 between 9.00am and 12.30pm.

If you require a review with our **haemophilia physiotherapist**, you may be invited to be seen in the outpatient clinics, or in the Physiotherapy department. You will be given details of where your appointment will be in advance.

If you require a review outside of these clinic times, you may be invited to attend the **haematology day unit** in the Royal Liverpool Hospital, based on ward 1A, First Floor.

Your appointments will be made in advance and sent to you in the post. A reminder text message will also be sent to you closer to your appointment date. If you are not able to attend your appointments, please call us to let us know, so that your appointment can be rescheduled.

If you are a new patient and you fail to come to your appointment two times in a row, you will be discharged back to the care of your GP. If you have been diagnosed with a bleeding disorder and fail to come to your appointments, you will be contacted by a haemophilia specialist nurse to support you with attending appointments.

## Inpatient Care

If you need to be admitted to hospital for treatment, we will always try to admit you to the haematology ward (ward 8B) in the Royal Liverpool Hospital. Sometimes, it may be more appropriate for you to be admitted to another ward, or different hospital site, for example after surgery. You will still be reviewed by the bleeding disorders team whilst you are an inpatient, and we will liaise closely with the other doctors and nurses looking after you.

## Treatment

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

## **Surgery**

Please help us by keeping us informed of any future operations or invasive procedures (such as dental work, endoscopy investigations, joint injections) so that we can provide you with the appropriate support. You may require treatment prior to the procedure.

We would be grateful 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. Please also ask any doctors or surgeons who are arranging an operation or procedure for you to contact us to discuss this. This will help prevent your operation or procedure from being delayed.

## **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 studying. You will also need to register with a local or university GP service.

When you tell us of your move, we can make sure that you have the contact details of the local haemophilia centre and make them aware, should you require emergency treatment during term time.

## **Planning a family?**

Bleeding disorders are often inherited, which means that they can be passed on to your children. If you are planning a family and would like to discuss this, please speak to us at your routine appointments, or contact us to arrange an additional appointment.

If you become pregnant, and you or your partner have a bleeding disorder, please contact us to let us know as soon as possible. You will then be reviewed in the joint obstetrics haematology clinic in Liverpool Women's Hospital during your pregnancy. You may require treatment or tests during your pregnancy and we will offer support and education to you and your partner.

## **Feedback**

Your feedback is important to us and helps us influence care in the future.

Following your discharge from hospital or attendance at your outpatient appointment you will receive a text asking if you would recommend our service to others. Please take the time to text back, you will not be charged for the text and can opt out at any point. Your co-operation is greatly appreciated.

## **Further information**

**How to contact us(for appointments, enquiries, and to speak with a member of the haemophilia team)**

**Telephone: 0151 706 3397**

**9.00am to 5.00pm,**

**Monday to Friday**

**Email: [bleedingdisorders@liverpoolft.nhs.uk](mailto:bleedingdisorders@liverpoolft.nhs.uk)**

**Out of hours: - outside office hours, on weekends or public holidays  
Tel: 0151 706 2000 (for emergency advice or treatment) ask to speak to the “Haematology Specialist Registrar on-call”**

**Haematology Ward (Ward 8B):  
Visiting times 2pm – 7pm  
Tel: 0151 706 2448  
Text phone number: 18001 0151 706 3397**

**The haemophilia society is the only national, independent charity for all people affected by bleeding disorders. They offer information about your condition, as well as:**

- **Choosing a career**
- **Benefits you might be entitled to**
- **Travel**
- **Volunteering, campaigning and fundraising**

**[www.haemophilia.org](http://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](http://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](http://www.nhs.uk)**

**Author: Bleeding Disorders Service, Haematology Liverpool  
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All Trust approved information is available on request in alternative formats, including other languages, easy read, large print, audio, Braille, moon and electronically.

يمكن توفير جميع المعلومات المتعلقة بالمرضى الموافق عليهم من قبل انتمان المستشفى عند الطلب بصيغ أخرى، بما في ذلك لغات أخرى وبطرق تسهل قراءتها وبالحروف الطباعية الكبيرة وبالصوت وبطريقة برايل للمكفوفين وبطريقة مون والإلكترونية.

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در صورت تمایل می‌توانید کلیه اطلاعات تصویب شده توسط اتحادیه در رابطه با بیماران را به اشکال مختلف در دسترس داشته باشید، از جمله به زبانهای دیگر، به زبان ساده، چاپ درشت، صوت، خط مخصوص کوران، مون و بصورت روی خطی موجود است.

زانیاری پیوندیدار بهو نه‌خوشانه‌ی له‌لایمن تراسته‌وه په‌سهند کراون، نه‌گهر داوا بکرنیت له فورماته‌کانی تردا بریتی له زمانه‌کانی تر، نیزی رید (هاسان خویندنه‌وه)، چاپی گه‌وره، شریتی دهنگ، هیلی موون و ئلیکترونیکی هه‌یه.

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