



# Welcome to the Haemophilia Centre

Information for patients, parents, and carers

The Kent Haemophilia and Thrombosis Centre is a specialist centre. It diagnoses and treats patients within the Kent and East Sussex area, who have:

- haemophilia
- · thrombosis, and
- · other bleeding disorders.



Entrance to the Kent Haemophilia and Thrombosis Centre, Kent and Canterbury Hospital

### **Our facilities**

The Haemophilia Centre is a self-contained unit, located behind car park 3. The entrance is off this car park, with a ramp for disabled access. To see where car park 3 is, view the Kent and Canterbury Hospital map (https://www.ekhuft.nhs.uk/kent-and-canterbury/).

Our facilities provide comprehensive care for both adults and children with bleeding disorders. It has two consultation rooms, a physiotherapy room, and a room for taking blood for testing. The patient waiting area also has a designated children's play area. We hold paediatric clinics in the Children's Assessment Centre on the same site.

- Our onsite laboratory provides a wide range of testing. This helps the haemophilia team:
  - o from your initial diagnosis in our laboratories
  - to any care you will need in hospital and in the community.
- We offer training and education to support patients, parents, and carers. This covers:

- · the administration of medications, and
- providing leaflets and literature on a range of bleeding disorders.
- We offer a home delivery service for haemophilia treatments, and a 24 hour on-call service.
- The **haemophilia team** includes a range of clinical and non-clinical staff, including:
  - consultants
  - haemophilia clinical nurse specialists (CNS)
  - physiotherapists
  - · laboratory scientists, and
  - administrative staff.
- We have **consultant clinics** on Monday, Thursday, and Fridays mornings.
- There is a multidisciplinary (MDT) clinic on a Tuesday afternoon.

If you have a problem with your appointment times, please call our routine enquiries number below.

- There is **direct access to physiotherapy** for patients with bleeding disorders. Please contact the centre on the numbers below to arrange an appointment.
- We work with the national Haemophilia and Bleeding Disorders Counselling Association (HBDCA) (https://www.hbdca.org.uk/). If you need **psychological support**, please contact the HBDCA or discuss this with a member of hospital staff at your appointment.
- Inpatient services.
  - Adult patients with haemophilia are generally admitted to the haematology ward (Brabourne Ward) at Kent and Canterbury Hospital.
  - Paediatric patients with haemophilia are admitted to one of the paediatric wards:
    - Padua Ward (William Harvey Hospital)
    - Rainbow Ward (Queen Elizabeth the Queen Mother Hospital).

Visiting times are generally open. Please discuss visiting with the nurses on the ward at the time.

• **WiFi:** you can access Trust WiFi by searching networks, and logging into EK-Hospital-Free-Internet. The password is **hospital.** You will need to provide an email address and accept the terms of use given.

#### Who is in the Haemophilia Team?

The Haemophilia Team is made up of:

- · Consultant and Centre Director
- Consultants

- · Haemostasis Manager and Nurse Specialist
- · Paediatric Haemophilia Nurse Specialist
- Haemostasis Sisters
- · Physiotherapists
- Health Care Assistant (HCA)
- · Service Manager for Haemophilia and Thrombophilia
- · Haemophilia Data Manager
- Business and Administration Manager
- Secretaries
- · Receptionists / administrators
- · Head Biomedical Scientist

# How do I get to the Haemophilia Centre?

- Rail: the nearest train station is Canterbury East, which is on the Dover to London Victoria line. It is a 15 minute walk from the hospital and a short walk from the bus station. Canterbury West is on the Ramsgate to Ashford line. It is a 20 minute walk from the hospital and short bus ride from the bus station.
- **Bus:** route number 25 and 25A run from Canterbury bus station to the hospital. It is a 15 minute walk from the bus station in Canterbury to the hospital.
- **Parking** is free for the first 20 minutes. Charges are displayed in the parking kiosks. There is a maximum charge per day. Weekly tickets are available.
- **Disabled parking** is available outside the main Outpatients building. If you have any issues around parking or accessing the Centre, please do not hesitate to speak to any of the staff.

For current information on how to get to the hospital, please go to the Getting to Kent and Canterbury Hospital (https://www.ekhuft.nhs.uk/kent-and-canterbury/) web page.

## **How do I contact the Haemophilia Centre?**

· Kent Haemophilia and Thrombosis Centre

Kent and Canterbury Hospital

**Ethelbert Road** 

Canterbury CT1 3NG

Telephone: 01227 783157 (non-urgent and routine enquiries)

Email (ekh-tr.haemophilia@nhs.net)

For any routine enquiries we will aim to respond by the end of the following working day.

• We have a designated **emergency number** that you can use for urgent clinical issues:

Telephone: 01227 783166 (Monday to Friday (excluding Bank holidays); open 8.30am to 5pm)

· Out of hours emergency contact

Telephone: 01227 783190 and ask for the Consultant on call for Haemophilia.

#### **Useful links**

The Haemophilia Society (https://haemophilia.org.uk/)
 The only national, independent and patient-led organisation for people affected by bleeding disorders.
 They work with the NHS to offer information and support. They also represent the interests of those affected by bleeding disorders.

- NHS (https://www.nhs.uk/) is the UK's biggest health website. It provides a health information service that puts you in control of your healthcare.
- The UK Haemophilia Centres Doctors' Organisation (UKHCDO) (https://www.ukhcdo.org)

The UKHCDO provides comprehensive and useful information on haemophilia and bleeding disorders. It also links to the National Haemophilia Database (NHD).

• World Federation of Hemophilia (WFH) (https://wfh.org/)

The WFH is an international not-for-profit organisation. It is a global network of patient organisations in 118 countries. It has official recognition from the World Health Organisation (WHO).

Women Bleed Too - Talking Red (https://haemophilia.org.uk/support/talking-red/)

This is a Haemophilia Society project. It aims to ensure bleeding disorders are a recognised condition among women, and that appropriate treatment and support is available.

• In-Hemoaction: playing and learning about haemophilia (https://elearning.wfh.org/resource/hemoaction-playing-cards-2/)

Using the universal language of pictures, children around the world can learn about hemophilia in a fun, easy to understand, and interactive way. The In-HemoAction cards teach children how to prevent bleeds and manage hemophilia.

- Medic Alert (https://www.medicalert.org.uk/)
  Medic Alert is a non-profit making, registered charity. It provides a life-saving identification system for individuals with hidden medical conditions and allergies.
- Live Well (https://www.nhs.uk/live-well/)

This NHS web page offers advice, tips and tools to help you make the best choices about your health and wellbeing.

Haemophilia Centre Locator (https://hclocator.org/centrelocator/)

The HCL will help you find your nearest five European Haemophilia Centres.

Haemtrack (https://haemtrack.mdsas.com/)

Haemtrack is a secure therapy recording system. It connects patients and clinicians through the Haemtrack phone apps and website.

#### This leaflet has been produced with and for patients.

If you would like this information in **another language**, **audio**, **Braille**, **Easy Read**, **or large print** please ask a member of staff. You can ask someone to contact us on your behalf.

Any complaints, comments, concerns, or compliments please speak to your doctor or nurse, or contact the Patient Advice and Liaison Service (PALS) on 01227 783145 (tel://+441227783145), or email ekh-tr.pals@nhs.net (ekh-tr.pals@nhs.net)

Patients should not bring large sums of money or valuables into hospital. Please note that East Kent Hospitals accepts no responsibility for the loss or damage to personal property, unless the property has been handed into Trust staff for safe-keeping.

**Further patient leaflets** are available via the East Kent Hospitals website (https://www.ekhuft.nhs.uk/information-for-patients/patient-information/).

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