

Registration, the National Haemophilia Database, and Bleeding Status Card

Information for patients and parents from the Haemophilia Centre

How do I/we register with the Haemophilia Centre?

Once a diagnosis has been confirmed, you or your child will be registered with the Haemophilia Centre at Kent and Canterbury Hospital. It is recommended that all patients with a bleeding disorder such as haemophilia are registered with a Comprehensive Care Centre such as at Canterbury. This means you have access to the services we offer, plus children will also have open access to their nearest paediatric ward. Below are the contact numbers in case of any queries.

We always advise that you speak to the Haemophilia Centre before contacting one of the wards.

Hospital	Ward	Contact number
Pembury Hospital, Maidstone Tunbridge Wells	Hedgehog Ward	01892 63 35 24 01892 63 35 25
William Harvey Hospital, Ashford	Padua Ward	01233 61 62 96
Queen Elizabeth the Queen Mother Hospital, Margate	Rainbow Ward	01843 23 45 78
Conquest Hospital, Hastings	Kipling Ward	01424 75 52 55
Medway Maritime Hospital	Penguin Assessment Unit	01634 83 00 00 Main switchboard



What is the National Haemophilia Database?

For us to be able to register you or your child we need to use The National Haemophilia Database. This is a register of UK patients (both adults and children) with all kinds of bleeding disorders.

The database is managed by the UK Haemophilia Centre Doctors' Organisation (UKHCDO). It collects information about you or your child, which is needed by the NHS to help plan haemophilia services, inform purchasing decisions, and learn more about the treatment and complications of these conditions.

More information is available on the UKHCDO website www.ukhcdo.org

What is the Bleeding Status Card?

Once registered, you will be issued with a Bleeding Status Card. This card will hold information about you or your child's bleeding disorder, the treatment needed, and your baseline factor levels (the level of the clotting factor when we diagnosed your bleeding disorder).

The card will have the details on how to contact the Haemophilia Centre in and out of normal working hours.

Please carry this card with you at all times.

If you are going to the dentist, doctor, or have an admission to hospital, please show staff your card. Ask them to contact the Haemophilia Centre or the out of hours on-call consultant for haemophilia on the numbers provided on the card.

The card will also have the following warnings.

- **No aspirin or non-steroidal anti-inflammatory drugs**
This is because anti-inflammatory drugs such as aspirin, ibuprofen, or nurofen can increase the risk of bleeding.
- **No intramuscular injections**
Intramuscular injections are avoided because of the risk of bleeding into muscle. The majority of medications can be given as an injection just under the skin, which would be safer and prevent bleeding into the muscle. If a medicine can only be given as an intramuscular injection then some treatment to minimise the risk of bleeding may be needed.

What happens if I lose or damage my card?

If you lose or damage your Bleeding Status Card or any of your details change, please contact the Haemophilia Centre for a replacement. A new card will be issued to you as soon as possible.

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 78 31 45, or email ekh-tr.pals@nhs.net

Patients should not bring in 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 had been handed in to Trust staff for safe-keeping.

Further patient leaflets are available via the East Kent Hospitals web site www.ekhufft.nhs.uk/patientinformation