

Adult Haemophilia Service

This leaflet explains more about the services offered by the Adult Haemophilia Service at St. George's Hospital. If you have any further questions, please speak to a doctor or nurse caring for you.

Who uses our service?

We care for people with bleeding disorders in south west London and beyond, with over 600 patients registered to us. We also investigate people who have had abnormal clotting results in their blood tests or people with a suspected bleeding tendency.

Some conditions we help people to manage include:

- Haemophilia A and B
- von Willebrand Disease
- Rare factor deficiencies (fibrinogen, FV, FVII, FX, FXI, FXIII)
- Platelet disorders (including Bernard Soulier Syndrome and Glanzmann's thromboasthenia)
- Unclassified bleeding disorders
- Acquired bleeding disorders.

Our team consists of dedicated consultants who are expert in managing patients with bleeding disorders, specialist nurses, highly specialised physiotherapists, a data manager and secretarial staff. We work closely with our laboratory staff who are essential to our assessments of bleeding conditions.

I'm worried I might have a bleeding disorder, what should I do?

If you suspect that you have a bleeding disorder please contact your GP for further guidance.

Common symptoms of bleeding disorders include issues with bleeding during or after surgery, problems with bleeding after having teeth extracted, losing a lot of blood during your periods when there is no other gynaecological explanation, recurrent nosebleeds with no established cause, severe spontaneous bruising and bleeding after child birth.

If you know that bleeding disorders run in your family you may also warrant further investigation.

I have a bleeding disorder, how do I register with the Haemophilia Centre at St. George's?

Please ask your current haematologist to refer you onto us or seek a referral from your GP.

Where will I be seen?

New referrals for investigation of bleeding symptoms are initially seen in our nurse-led clinic in Clinic 5 on Thursday afternoons between 2pm to 4pm. You'll be asked questions about your bleeding history and some blood samples may be taken. Please present to the haematology-oncology outpatients' department to check-in.

Our routine clinic appointments also take place in Clinic 5. They are held most Wednesdays between 2pm to 4.30pm.

You may be seen on the Ruth Myles Day Unit. This is where we see patients for blood tests and treatments. Please be advised this is not a walk-in service and appointments must always be made in advance.

What care will I receive as a patient registered to this service?

If you have a **severe bleeding disorder** you will be seen every six months for a review in our outpatients' clinic with a doctor, nurse, and physiotherapist. If you take clotting factor regularly at home we'll review your regimen. Our data manager handles the administration for your home delivery of clotting factors.

Patients with a **moderate or mild bleeding disorder** will be seen annually or may have a telephone review with one of the specialist nurses.

We can provide you with onward referrals for other specialities for issues associated with your bleeding disorder such as orthopaedics (bone and joint specialists), dentistry, hepatology (liver), gynaecology and obstetrics (women's health issues), urology, care of the elderly and genetic counselling.

We can provide you and your family/carer with support, advice and education over the telephone or in the hospital. Our holistic care aims to minimise the impact of your bleeding disorder on your quality of life.

What can I do to help?

- Please telephone us for advice if you are having bleeding issues which you are struggling to manage at home or if there is anything worrying you about your bleeding disorder.
- Carry your bleeding disorders card on you at all times and ask us for a replacement as required.
- Inform us of any upcoming invasive procedures with as much notice as possible. This includes surgeries, endoscopy, biopsies and dentistry. If in doubt, please telephone and inform us.
- Please attend your appointments on time or telephone in advance to cancel them (see below).
- Keep your Haemtrack up to date with records of your bleeds and factor usage.

What do I do if I have an emergency?

In the event of an emergency please attend your local Emergency Department.

Where possible please inform the haemophilia office (or haematology registrar if out of hours) of your attendance so that we are aware you're on the way.

What do I do if I have a bleed or injury?

- Please contact us if you have a bleed.
- Treat yourself promptly with clotting factor, desmopressin or tranexamic acid as instructed by the Haemophilia Centre team.
- If you are unable to treat yourself please telephone the haemophilia office immediately so we can assess you over the telephone and advise you appropriately.
- If the bleed occurs out of hours please contact the haematology registrar on call.
- Further information can be found in our patient information leaflets.

How else can St. George's support me?

- St George's University Hospitals can provide an interpreter if one is required, please ask the nurse to arrange this.
- Spiritual Support is available for all major religions and the Spiritual Centre is on Ground floor Grosvenor Wing
- We welcome your feedback on our service and there is a satisfaction survey available in the outpatients department, wards and day units for you to complete.

Clinics, locations, and contact details

If you have any questions or concerns, please contact the haemophilia team on 020 8725 0763 (Monday to Friday, 8am to 5pm).

Out of hours, please contact the hospital switchboard on 020 8672 1255 and ask for the on-call haematology registrar.

Outpatient Haemophilia Clinics

Adult Haemophilia Clinic is held most Wednesdays between 2pm to 4.30pm.

Location: Haemostasis and Thrombosis Clinic, Clinic 5, Ground floor, St James wing, St George's Hospital.

Nurse-led new patient clinic is held each Thursday from 2pm to 4pm.

Location: Please present to Haematology-Oncology outpatients department, Ground floor St James wing.

If you need to reschedule an outpatient appointment, then call haematology-oncology outpatients (HOOP) Tel: 020 8725 3535.

Telephone Clinic is conducted the second and third Wednesday of each month between 2pm to 4pm.

To reschedule a telephone clinic please contact the haemophilia office directly.

Haematology Day Unit

Ruth Myles Day Unit, 2nd floor, St James wing, St George's Hospital. Tel: 020 8725 1680

Adult Haematology Inpatient Wards

Ruth Myles Ward, 2nd floor, St James wing, St George's Hospital. Tel: 020 8725 2442

Gordon-Smith Ward, 3rd floor, Lanesborough wing, St George's Hospital.
Tel: 020 8725 5873

Useful sources of information

If you have any further questions please contact us on 020 8725 0763 or e-mail haemophilia@stgeorges.nhs.uk

We also have useful links and information available on our hospital website:

<https://www.stgeorges.nhs.uk>

Please enter haemophilia into the main search bar to find us.

For more information leaflets on conditions, procedures, treatments and services offered at our hospitals, please visit www.stgeorges.nhs.uk

Additional services

Patient Advice and Liaison Service (PALS)

PALS can offer you on-the-spot advice and information when you have comments or concerns about our services or the care you have received. You can visit the PALS office between 9.30am and 4.30pm, Monday to Friday in the main corridor between Grosvenor and Lanesborough wings (near the lift foyer).

Tel: 020 8725 2453 **Email:** pals@stgeorges.nhs.uk

NHS Choices

NHS Choices provides online information and guidance on all aspects of health and healthcare, to help you make decisions about your health.

Web: www.nhs.uk

NHS 111

You can call 111 when you need medical help fast but it's not a 999 emergency. NHS 111 is available 24 hours a day, 365 days a year. Calls are free from landlines and mobile phones.

Tel: 111

AccessAble

You can download accessibility guides for all of our services by searching 'St George's Hospital' on the AccessAble website (www.accessable.co.uk). The guides are designed to ensure everyone – including those with accessibility needs – can access our hospital and community sites with confidence.



Reference: CLH_AHS_01 **Published:** September 2019 **Review date:** September 2021