NHS
University Hospitals Birmingham
NHS Foundation Trust

Caring for the person with a bleeding disorder

Building healthier lives

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To see all of our current patient information leaflets please visit
www.uhb.nhs.uk/patient-information-leaflets.htm

Contents

The Team

Consultant Haematology Doctors

Dr Charles Percy
Dr Will Lester
Dr Gill Lowe

Nursing team

Helen Hupston	Clinical Nurse Specialist Team Leader
Koomaravel Nagapachetty (Naga)	Clinical Nurse Specialist
Pam Green	Clinical Nurse Specialist and Community Nurse
Debra McGovern	Clinical Nurse Specialist
Telephone:	(0121) 371 4995/7

A voicemail facility is available

Research team

Elizabeth Dwenger	Research Nurse
Martin Pope	Project Assistant
Telephone:	(0121) 371 3594 or mobile 07795952168

Administration

Camillia Edmead, Secretary to Dr Lester and Dr Lowe, is available on 0121 371 4996. There is a voice mail facility available, if she is unable to answer your call she shall endeavour to return your call by the end of the next working day.

April Greenway, Secretary to Dr Percy, is available on 0121 371 7871.

Data

Janice Ward	Data Analyst

Specialist Haemophilia Physiotherapist

Victoria Morris	Senior Physiotherapist Team Leader

This booklet has been designed to offer support, advice, guidance and education to patients, relatives, carers, friends and extended family about bleeding disorders and how they may affect the person and, in addition, to provide you with information about the Centre with which you are registered.

Useful information

- We are situated on the ground floor within the Cancer Centre, Heritage Building, Queen Elizabeth Hospital Birmingham (QEHB), Edgbaston, Birmingham, B15 2TH. Although we are located in the Cancer Centre, we are a completely different speciality.
- The Haemophilia Unit is open 08:30–16:30 Monday to Friday, excluding bank holidays.
- The haemophilia team aim to return non-urgent enquires before the end of the next working day.
- If you have an urgent problem and need to be seen outside of the Haemophilia Unit's hours, you should contact Switchboard on (0121) 371 2000 and ask to be directed to the on-call haematology registrar. They will arrange review on the Acute Oncology Unit (AOU) which is located on Ward 622. If your condition is felt to be more serious, they may direct you to attend the Emergency Department.
- Parking – Our nearest car park is Car Park D, which is located opposite the Cancer Centre. Disabled spaces may be available on the ground floor. Alternative car parks are found on either side of the hospital. One of these is located at the top of the drive by Busy Bees nursery. Please ask for a map if required.
- Inpatient ward visiting times are 11:30 until 20:00.

Who we are and what we offer

QEHB is a Comprehensive Care Haemophilia Centre (CCC). We care for a wide range of inherited bleeding disorders that we diagnose and treat. These include:

- Haemophilia A and B
- Von Willebrand Disorder
- Other clotting factor deficiencies
- Inherited Platelet disorders
- Other less common and rare bleeding disorders

We provide the following services:

- A team of dedicated specialist doctors and nurses with 24-hour medical on call cover
- Emergency assessment and treatment of bleeds
- Regular assessments, reviews and screening
- Acute assessment and treatment
- Diagnostic services
- Genetic testing and counselling
- Specialist haemostasis laboratory
- Support and counselling
- Specialist physiotherapist care
- Home treatment
- Home delivery services
- Social worker
- Dental and restorative treatment
- Educational support for patients and carers
- Information and advice for healthcare professionals, patients, friends and employers.

We work closely with a number of other specialities in order to provide comprehensive care for our patients. These include:

- Orthopaedics
- Dental and restorative treatment
- Genetics
- Genetics counsellor
- Liver specialists
- Infectious Diseases
- Obstetrics and Gynaecology
- Ear, nose and throat (including a joint clinic once a month with a haematology doctor and ear nose and throat doctor)

Clinics

Clinics for patients are held:

- Mondays – Thrombosis Clinic 08:30–12:30
- Tuesdays – Haemophilia and bleeding disorders 08:30–12:30

If you require an interpreter please contact (0121) 371 4756 or you can email them at **interpreting.service@uhb.nhs.uk** as soon as you have received your appointment letter.

It helps to have your hospital or NHS number when booking interpreting services.

We recommend six monthly reviews for people who have severe bleeding disorders and at least every 12–24 months for those with mild to moderate bleeding disorders. This allows for assessment which can identify new or potential problems as soon as possible and to implement changes and help if required.

At clinic we shall aim for you to be seen by the multidisciplinary care team including the consultant, specialist nurse and physiotherapist. This should also be the case after an acute bleeding episode.

If you would like to contact the physiotherapist please leave a message with the haemophilia nurses who shall pass your details on.

Research

We have an active portfolio of research studies across all types of bleeding disorders. If you would like to express an interest and to see if you are eligible to participate in research studies, please contact our research team.

Feeling unwell?

If you have a bleed and need to attend the Haemophilia Unit for treatment, please telephone beforehand to let staff know you are coming. This will help us prepare for your arrival, to order any investigations you may need and this may shorten your attendance time. If you are unsure if you have a bleed and need advice, please contact the haemophilia nurses.

If you have a bleed outside of normal working hours (e.g. evenings, weekends, bank holidays), you should contact the on-call haematology registrar via Switchboard on (0121) 371 2000. Please inform the doctor of your diagnosis and your problem. You may be advised to attend the Acute Oncology Unit (AOU) located on Ward 622, Level 6, QEHB if appropriate. Alternatively, or if you have a more serious problem, you will be advised to attend the Emergency Department. On arrival at the Emergency Department, show staff your bleeding disorders card to make them aware of your diagnosis.

In the event you have an accident or are seriously unwell and have to dial 999, show the ambulance staff your bleeding disorders card. If you are admitted to another hospital, then again you should show staff your bleeding disorders card and ask that they contact the Haemophilia team at QEHB as soon as possible. If needed there are doctors available at all times who can be contacted through the hospital Switchboard.

If you do not have a bleeding disorders card please ask the team for one.

What is Haemophilia?

Haemophilia is a lifelong, inherited bleeding disorder whereby there is a complete absence (missing) or reduction (short of) level of a clotting factor, factor VIII (8) in haemophilia A or factor IX (9) in haemophilia B.

It is also possible to have deficiencies or reductions in any of the other clotting factors, and some of these conditions can cause bleeding disorders.

When there is a problem with certain clotting factors, the body cannot form a stable blood clot after injury, leading to ongoing bleeding and sometimes spontaneous bleeding (bleeding for no clear reason); this is why factor treatment is required.

How are bleeding disorders inherited?

This depends on the disorder. The doctor or nurse will be able to explain more.

Women with bleeding disorders

Some women experience heavy periods. You may hear the word, "menorrhagia." This means heavy and prolonged periods.

Every woman is different, and what is considered 'normal' bleeding during a period for one woman may be 'excessive' for another. The average amount of blood lost during an average period is 30–40ml. Blood loss of 80ml or more is considered to be 'heavy'. If your period last for more than seven days, you are soaking through sanitary protection every two hours or less or your clots are bigger than a 50p piece then you should discuss this with the haemophilia team. If appropriate we can refer you to a Gynaecologist for further treatment.

If you suffer with heavy and longer periods you may subsequently have low levels of iron in your blood, which can cause anaemia. You may feel weak and tired. If you do get these symptoms please talk to a member of staff who can help with these symptoms.

Pregnancy, planning and labour

We work closely with Birmingham Women's Hospital (BWH), which can offer a clinic appointment with an obstetrician and a haematology doctor who are able to discuss pregnancy plans. Precautions may be put in place if your baby has, or is suspected to have, a bleeding disorder.

The management of childbirth will depend on the needs of the mother and baby. We work closely with BWH. If the mother is not at BWH or near a haemophilia centre, the teams should liaise closely with the haematology team at QEHB.

If needed, we will put a birthing plan in place beforehand so that we are prepared for the safe arrival of your baby.

Having an epidural or a caesarean section should be discussed with your haemophilia doctor.

Breastfeeding is safe for women who wish to do so.

Your baby should have Vitamin K administered orally and not intramuscular route. The use of tranexamic acid is safe for breastfeeding as is factor concentrate and desmopressin.

Acquired Haemophilia

This condition is not inherited; both men and women can be affected. Often one of the first signs of acquired haemophilia is extensive bruising. People may present with soft tissue bleeds with no previous history of excessive bleeding. This is a very rare condition and the importance of prompt treatment and care by a specialist is essential. If you would like further information on acquired haemophilia please talk to a member of the team.

Von Willebrand Disorder (VWD)

Von Willebrand Disorder (VWD) is a genetic disorder caused by missing or defective von Willebrand factor (VWF), which is a clotting protein that sticks blood clots to the blood vessel wall.

There are three types of VWD. These are:

- Type 1 – the VWF works normally but the amount is reduced. It is the most common type. Treatment is usually with desmopressin and tranexamic acid.
- Type 2 – the VWF does not work normally, even if the amount is normal. Patients usually require factor concentrate and tranexamic acid.
- Type 3 – Severe condition (like haemophilia) with absent VWF. This is rarer and has no response to desmopressin and requires factor concentrate and tranexamic acid.

Common symptoms of VWD include:

- Mucosal bleeding e.g. mouth bleeding
- Gastrointestinal bleeds
- Epistaxis (nose bleeds)
- Menorrhagia (heavy periods)
- Large bruising on multiple sites

How are bleeding disorders diagnosed?

We will start by asking you a number of questions, such as whether you've had any operations where bleeding lasted longer than expected. If you bruised easily as a child this maybe an indicator of a possible bleeding disorder. Maybe you have a family history where your mother, siblings, uncles, brothers, father or any other family members have any bleeding concerns? We may take your blood in order to check for clotting levels and any other abnormalities.

Signs of possible bleeding disorders

- A tendency to bruise easily
- Excessive bleeding from skin cuts/mouth/tongue mucosal injuries – which may take a long time to stop
- Bleeding after dental extractions
- A tendency to bleed into joints and/or muscles (symptoms can be pain, swelling and limitation of movement)

- Soft tissue bleeding and formation of large bruises (haematomas)
- Bleeding during or after surgery
- Central nervous system (CNS) bleed
- Excessive bleeding after having a baby
- Heavy periods in women who are carriers of haemophilia with low clotting factor levels.

Who is tested for a possible bleeding disorder?

- People who display symptoms for example bleeding from cuts/ dental/surgery
- People with a diagnosis of haemophilia or VWD will be tested in order to determine the severity
- Females who are related to a person with haemophilia (who may have excessive bleeding)
- Female carriers seeking antenatal diagnosis (in pregnancy or before pregnancy). A family tree is helpful to identify heritage of any bleeding tendencies

National Haemophilia Database (NHD)

The National Haemophilia Database (NHD) is a register of UK patients with all kinds of bleeding disorders. The database is managed by the UK Haemophilia Centre Doctors' Organisation (UKHCDO) - the doctors who treat bleeding disorders in the UK. This database collects information from Haemophilia Centres, which is required by the NHS and which helps us to plan haemophilia services, inform purchasing decisions and to learn more about the treatment and complications of these conditions. This helps to ensure that patients continue to receive high quality care with safe and effective treatments. Information collected includes diagnosis, treatment and complications of treatment (including virus transmission) and complications of the conditions itself. This information is requested by the NHS. If you have further queries please visit their website **www.ukhcdo.org.**

Recognising the clinical signs of a bleed

- Patients may report a tingling, bubbling sensation when the bleed starts
- Pain
- Heat
- Swelling
- Restricted movement

What are inhibitors?

Some patients may develop inhibitors which are when a person's immune system recognises the factor replacement as a foreign protein and produce antibodies to it.

This may result in the clotting factor treatment not working properly. If you are diagnosed with an inhibitor, the doctor who you see will discuss management and you may consider use of other clotting factor products (referred to as bypassing agents).

Think of an inhibitor as Pacman. Your body may develop an inhibitor that detects factor as a foreign body (invader) by eating them; this is when a bypassing product is used.

Care and treatment of a bleed

Many bleeding disorders are treated by replacing the missing clotting factor, which is administered via a slow intravenous infusion; this is an injection into your vein.

You will be given a bleeding disorder card and you should carry this with you. It will have your name, date of birth, your centre details, your bleeding type and treatment. If you do not have one please contact the Haemophilia Unit.

Treating a bleed as soon as possible gives you the best outcome. Delay in treatment may result in potentially irreversible complications, such as joint damage.

Some of you may be on prophylactic treatment (called prophylaxis) - this is in order to prevent or reduce bleeds. Prophylactic treatment can be given at different time intervals e.g. once a week to 2–3 times a week depending on what factor replacement product you are on.

You may be on "on demand treatment" where treatment is given in the event of a bleed or before any interventions, such as surgery or dental treatment.

You may be prescribed tranexamic acid, which is something called an antifibrinolytic. This means it can help to strengthen blood clots by preventing them breaking down.

Desmopressin treatment is usually for patients with Type 1 VWD, some platelet function disorders and unclassified bleeding disorders. Desmopressin is a synthetic hormone, not a blood product. Desmopressin works by releasing FVIII (8) from the blood vessel wall. You must have some FVIII present in your body for this to work. This treatment is not suitable for people with haemophilia B.

Desmopressin is given as a subcutaneous injection (just under the skin), however is available as an infusion or nasal spray.

We advise our patients to restrict to 1.5 litres of fluid in a 24-hour period as the body may retain water after desmopressin.

Patients may experience the following symptoms, which should pass in time:

- Facial flushing and feel warm
- Headaches
- Abdominal pain and feeling of sickness
- Sweating
- A few people have allergic skin reactions

Some patients may be able to self-administer your own treatment and know when you have had a bleed. If you feel that you may have sustained a bleed, you should let the haemophilia team know and complete your treatment on to Haemtrack (this is explained in the next section).

Please let the nurse or doctor know if this is a new onset of a bleed or a recurrent bleed, and inform us if you have treated and, if so, how much factor.

Home treatment

If you have frequent bleeds and require treatment you may be interested in learning to self-administer your factor at home. Being able to give your own treatment means that you can give treatment to prevent bleeding episodes, or in the event of a bleed to give prompt treatment which aides a quicker recovery. Ideally we would like you to learn to self-treat. However, if you would like a carer to help we can arrange teaching for both. If you have a port, fistulae or an in dwelling device then please tell a member of staff who can ensure that you are caring for this safely and are happy to self-manage.

You can request a home delivery service where the factor is delivered directly to your home in an unmarked vehicle to maintain your confidentiality. This can be time saving and more convenient than attending the hospital to collect treatment. However, if you would like to collect your treatment from pharmacy at the hospital that is no problem. Please call the haemophilia team with advance notice in order to get the prescription done and pharmacy to order in your treatment.

Any ancillaries required such as sharps bin, syringes etc. should be collected from the Haemophilia Unit. We request that there is a minimum of 48 hours' notice for the request of any prescription which should be made to the haemophilia team.

Haemtrack is an electronic system which enables patients to keep a record of their treatment using a confidential and secure application. Patients are able to input their treatment including prophylaxis treatment and if they have an acute bleeding episode. You can enter the location of the bleed, how much treatment you have used and how long you have needed treatment for. This system allows the haemophilia team to be able to see if you are experiencing any problems that we may be able to offer additional help and support.

It is part of the contractual agreement that patients who have home treatment must keep a record of treatment, preferably by the online home record keeping Haemtrack **(www.haemtrack.nhs.uk)**.

Please ask the team for advice about this service.

If you are unable to access a computer a paper, record must be kept which must be taken to your routine follow up appointment.

Part of the home treatment agreement is that patients must attend their booked routine appointment you will need to sign an agreement to accept these conditions.

Reconstitution of factor

A factor reconstitution leaflet will be enclosed in each individual factor. If you need any further education or support on the mixing and administration of your treatment the nursing team are happy to support you with this.

The basic principles of reconstitution –

- Wash your hands prior to mixing the factor
- Using the supplied equipment in your factor treatment mix your factor with the water for injection supplied in your kit

Record the dose administered and the batch number of concentrate on Haemtrack or if you use a paper record please bring to your next consultation or visit to the haemophilia unit.

Emergency treatment

IF IN DOUBT TREAT!

Life threatening bleeds

These can include:

- Central nervous bleeds (CNS)
- Gastrointestinal tract (GI)
- Airway – throat/mouth
- Iliopsoas (muscle bleed)

Head injury/CNS

A head injury, intracranial or central nervous bleed (CNS) bleed can lead to long-term disabilities or could be life-threatening. Treat as soon as a bleed is suspected if you or someone else is able to do so. You should contact the haemophilia team for advice and call an ambulance if deemed appropriate.

A 100% factor dose rise should be given. If you are unsure of the 100% dose rise for you please contact the ahemophilia team. Diagnosis of a bleed is based on clinical assessment and scan findings.

Gastrointestinal tract (GI) bleed

Immediately give yourself treatment if you are able to do so. We shall continue to give you factor until the bleeding has stopped. Melaena (blood in the stool) may be a sign of an acute gastrointestinal haemorrhage. You should contact the haemophilia team for advice and call an ambulance if deemed appropriate.

Airway

If you are immediately in danger, you should call an ambulance. If you are able to do so, give yourself factor treatment.

Psoas (Groin)

If you are able to do so, give your factor as soon as possible. You should contact the haemophilia team for advice and attend for review if requested.

Joint bleed

If you sustain a joint bleed and are unsure how much to treat or for how long, then please contact the haemophilia team and we can advise. A joint bleed in people with mild haemophilia should be considered for treatment as bleed severity can often be underestimated. Each bleed should be assessed individually. Physiotherapy will aid recovery.

Muscle bleed

Muscle bleeds are usually identified when there is soft tissue swelling and pain not directly related to a joint. Treatment duration depends on the bleed severity. The haemophilia team will advise you on this.

Nose bleeds

You should sit in a forward facing position applying firm pressure with a compress soaked in ice water, on the soft part of the nose for 10–20 minutes or until bleeding stops. If you self-treat, and are able to do so, administer factor. If you are unsure of the dose you need please ask the team. The use of tranexamic acid should be considered.

Mouth bleeds

If it is a localised bleed which you are able to see and reach, then you should apply pressure with damp gauze until bleeding stops. Use tranexamic acid if you have a supply. We would suggest that you have a soft diet for a couple of days.

Haematuria (blood in your urine)

Do not give yourself any treatment without advice from the haemophilia team, as you risk developing a clot if treatment is inappropriate. You should increase your fluid intake to reduce the risk of colic due to clots.

Lacerations (cuts)

Treat superficial cuts and grazes by applying pressure until the bleeding stops. If bleeding continues then please administer factor at home, if you are able to do so, and then contact the haemophilia team for further advice.

PRICE

The principal of PRICE is used even if treatment is given. It stands for:

- Protection – try to take the weight off the joint
- Rest – this may help the healing process
- Ice – this may help with the swelling and pain. Do not apply ice directly on the skin. Place the ice in a damp cloth or tea towel before applying to the affected area. Apply for a maximum of 20 minutes. This can be done every two hours if required. Check your skin frequently when applying ice to ensure that it is not causing damage to your skin
- Compression – such as a support bandage/Tubigrip
- Elevation – drain the blood away from the affected joint

Pain management

Acute and chronic pains are common in patients with severe and moderate bleeding disorders. Please talk to your nurse or doctor. If required, a referral to the pain management team can be made for chronic pain. Cold packs, immobilisation, splints and crutches may help with an acute bleeding episode with follow-up care of the multi-disciplinary team, including the physiotherapist.

Physiotherapy (after a bleed or injury)

The input of physiotherapy is highly recommended to aid joint recovery after a bleed or injury to minimise any long-term complications, however it must be used at an appropriate time. Initially after a bleed, a period of bed rest is recommended so that the bleed does not deteriorate/bleed again. However it is important to safely restore physical movement after the initial period of rest. The haemophilia team should be contacted for advice. If you have an injury or trauma to the joints or muscles causing swelling or a bleed and your symptoms are not improving, please contact the Haemophilia Unit to arrange to see our specialist physiotherapist.

Physiotherapy (for joint care and wellbeing)

For patients with haemophilia a joint score assessment should be completed once a year by our specialist physiotherapist to assess the condition of your joints and monitor them over time. Following this assessment you may be given advice, exercises and follow-up physiotherapy treatment appointments if this is likely to benefit you.

Physiotherapy treatment can also be beneficial for patients with:

- Chronic pain/problems (ongoing joint or muscle pains)
- Deteriorating balance, unsteadiness or falls
- Difficulty increasing your activity levels. You may be having difficulty in starting a new activity or increasing your level of activity for some reason.

Please contact the physiotherapist if you would like to discuss this further.

Physiotherapy (following surgery)

The input from a physiotherapist can be very beneficial for a good recovery from your operation especially if you have had surgery involving the joints, ligaments or muscles. If you have physiotherapy follow-up appointments elsewhere and further advice is required by either yourself or your physiotherapist, the specialist physiotherapist at the Haemophilia Unit can be contacted. If you have not been offered physiotherapy after your operation and you think it might be beneficial please contact the haemophilia team to enquire about an appointment.

Elective (planned) surgery, emergency surgery and invasive procedures

If you are due to have a planned procedure it may be that you will need factor replacement treatment. Please inform the haemophilia team as soon as you can. Tell us what you are having done, where and when. We shall put a treatment plan in place for you and communicate with appropriate teams.

Factor is administered 30 to 60 minutes before your procedure. If you are able to and no bloods are required, we may ask that you self-treat prior to the procedure, especially if you are at another hospital. If this isn't an option or we would like to take bloods from you then we may be able to arrange for our community nurse to attend the hospital to see you before and after your procedure if needed.

In an emergency situation there are supplies of factor across many hospitals around the West Midlands which have some factor in stock to be given in an emergency. However this cannot be guaranteed, therefore it is important that should you have any treatment at home and are not attending QEHB you should take your treatment with you. Always make sure that the attending hospital know you have a bleeding disorder and should contact the haemophilia team. Carrying your bleeding disorders card is important to alert medical staff that you have a bleeding disorders diagnosis.

Patients with bleeding disorders should not receive intramuscular injections. These injections are given deep in to the muscle, which may cause bleeding at the injection site.

Dental services

There is a Dental Department available here at QEHB. They are located in Outpatients Area 2. This service can be accessed by those registered with the Haemophilia Unit.

Clinics are held on Tuesday afternoon and Wednesday morning. Their contact number is 0121 371 5994 – they have a voicemail facility if unable to answer immediately but you can also contact them via email at **HaemophiliaDentalTeam@uhb.nhs.uk**

For persons with bleeding disorders, good oral hygiene is very important prevent gum disease, which can induce bleeding.

You should attend dental examinations regularly to maintain a good level of oral care. You should brush your teeth twice a day with a medium texture brush or an electric toothbrush, including the use of dental floss wherever possible.

Please contact the Dental Department directly to book any appointments including urgent ones; please only contact the Haemophilia Unit if this is your first appointment so that a referral can be made.

If you require any interventional procedures which may cause bleeding, please contact the haemophilia team so that appropriate treatment may be given. The dentist shall instruct you if treatment would be required.

What to avoid

In the event that the use of anti-platelet agent (such as aspirin) or an anticoagulant is ever discussed with you please discuss with haemophilia team first.

The use of painkilling tablets such as ibuprofen or diclofenac may be useful for you but again should be discussed with the haemophilia team before starting.

The use of intramuscular (I.M) injections should be avoided as these can result in a bleed. If you require a vaccination this should be given as a subcutaneous injection, which is given just under the skin.

General wellbeing

It is advisable for all individuals to take part in regular activities for overall health and wellbeing. Evidence suggests that muscle strength and balance-related exercise can improve current symptoms and also improve future health outcomes, especially for those who may require periods of rest or hospitalisation.

Being physically active may help reduce the risk of heart disease, stroke and type II diabetes.

Being active doesn't have to mean hours at the gym; you can find many ways to build more activity into your daily life. For example, try getting off the bus one stop early on the way home and walking the remainder of your journey.

For more ideas on being active the following website may be helpful: **www.nhs.uk/live-well/exercise/get-active-your-way**

Healthy eating

The key to a healthy diet is to:

Eat the right amount of calories for how active you are, so that you balance the energy you consume with the energy you use. If you eat or drink too much, you'll put on weight. If you eat and drink too little, you'll lose weight.

Eat a wide range of foods to ensure that you're getting a balanced diet and that your body is receiving all the nutrients it needs.

Don't get thirsty. We need to drink plenty of fluids to stop us getting dehydrated – the government recommends 6–8 glasses every day.

This is in addition to the fluid we get from the food we eat. All non-alcoholic drinks count, but water and lower-fat milk are healthier choices.

For further information on eating healthy take a look at the following website:
www.nhs.uk/live-well/eat-well/eight-tips-for-healthy-eating

Stopping smoking – this is a recommendation for a healthier lifestyle, as having a bleeding disorder does not remove your risks of suffering with smoking-related illnesses. Contact your local stop smoking sensation team or your GP for support.

Issues relating to sex

Patients with haemophilia can enjoy and practice safe sex. If you self-treat with factor treatment it may be best if you can have treatment prior to intercourse. If you sustain a muscle bleed, e.g. a groin bleed or a joint bleed, this may sometimes be the result of sexual activity.

Some women may have vaginal bleeding during and after sex.

People may bleed different amounts so if you are concerned or should it persist for more than a couple of days then call your haemophilia team.

Men with severe or moderate haemophilia may find that masturbation causes bleeds of the wrist, forearm and sometimes genital bleeds. Having treatment prior to sexual activities may reduce the risk of sustaining a bleed. If you have pre-existing joint problems, taking these into account may also help reduce the risk of bleeds related to sexual activity.

Men may also see blood in their sperm. This is known as haematospermia and whilst often it's nothing to worry about, you should talk to your doctor or nurse.

Take care of yourself and your partner and use protection from sexually transmitted diseases or an unwanted pregnancy. There are condoms on the Haemophilia Unit should you need any.

Psychosocial issues

We appreciate that having a bleeding disorder does not just have an impact on your physical health but also on your psychological wellbeing. If you are struggling with any emotional difficulties, please talk to us. Anything you say will be treated with respect, honesty and in confidence.

If you have any financial concerns, please talk to a member of the team and we can help direct you to the appropriate people.

Bleeding disorders can be complex conditions which may be difficult to explain to other people. If you would like one of the team to explain your diagnosis to a family member, friend, carer, partner, college or work place that is not a problem. We can discuss the physical, psychological, emotional complexity of your condition in terms which they can understand.

Vaccinations and immunisations

If you require vaccinations or immunisations please ensure that these are only administered subcutaneous (under the skin) rather than intramuscularly, which may cause a muscle bleed. If you have any queries please contact the haemophilia team prior to treatment.

Travel advice

If you are travelling abroad and require a customs letter, please let the unit know with at least seven days' notice. This will allow you to travel with your factor treatment, equipment and any medication. We can also advise you of any local haemophilia centres as close to your destination as possible should you need to attend. Travel advice can be accessed on the internet: **www.euhanet.org/centrelocator**

Feedback

We welcome any feedback or comments form you on how to improve our service. We can be contacted on email at **haemophilia.birminghamadult@nhs.net** or telephone on 0121 371 4995. You can also leave feedback in the suggestion box located in the waiting room on the Haemophilia Unit. Suggestions and comments may be left anonymously.

Useful websites and contacts

PALS

Email: pals@uhb.nhs.uk

Tel: 0121 371 3280

Haemophilia.org.uk

Nhs.uk

Wfh.org

Immigration enquiries

Dawn Doherty
Tel: 0121 371 5327

Faith and community centre

Level 1, QEHB
Tel: 0121 371 4570

www.citizensadvice.org.uk

Your details

Name: DOB: NHS No: Address:	Diagnosis: Inhibitor: Factor levels: Allergies/comments:
Treatment: Dose for emergency treatment based on 100%	

Please use the space below to write down any questions you may have and bring this with you to your next appointment.

The Trust provides free monthly health talks on a variety of medical conditions and treatments. For more information visit www.uhb.nhs.uk/health-talks.htm or call 0121 371 4323.

Haematology
Queen Elizabeth Hospital Birmingham
Mindelsohn Way, Edgbaston, Birmingham B15 2GW
Telephone: 0121 627 2000

PI19/2104/01 Author: Helen Hupston
Date: June 2019 Review date: June 2021