

Clinical haematology

Mild or moderate haemophilia - how will it affect my life?

Information for patients

Introduction

Haemophilia is a condition that affects the blood's ability to clot. It is usually inherited. This leaflet explains more about haemophilia, how to live with the condition and what support is available. It has been written for:

- teenagers or adults with mild or moderate haemophilia
- parents of a child with mild or moderate haemophilia
- carriers of haemophilia A or B who have low levels of clotting factor themselves

It may also be useful for:

- other family members who may be affected
- healthcare professionals, teachers or employers

This leaflet supports the advice you have been given at your haemophilia centre. If you have any questions about any aspect of your condition please speak to the haemophilia centre staff.

Symptoms of haemophilia

Normally, when you have a cut or wound clotting factors in your blood mix with blood cells called platelets to make your blood sticky. This makes the bleeding stop eventually. People with haemophilia do not have as many clotting factors in their blood so it will take much longer to clot, so they bleed for longer than usual. This is the main symptom of haemophilia. Other symptoms include:

- bleeding gums
- nosebleeds that take a long time to stop
- mouth bleeds
- skin that bruises easily
- pain and stiffness around your joints, such as elbows, because of bleeding inside the body (this is more typical of severe haemophilia)

Haemophilia is classified as mild, moderate or severe depending on your clotting factor level. The lower the clotting factor level, the more likely it is that you will have bleeding problems and these will happen more often.

Your clotting factor level will be written on your inherited bleeding disorder (IBD) information card.

Tests and diagnosis

Haemophilia might be suspected, expected or completely unexpected. You may have a family history of the condition. While the diagnosis may come as a shock, many adults find it helps them to make sense of previous experiences of bleeding. It can be a relief to know that something can be done to stop bleeding problems in future.

Our specialist haemophilia centre is experienced in the diagnosis and treatment of inherited bleeding disorders. The haemophilia specialist will ask about your personal and family history of bleeding. This will include any experiences of bleeding problems following surgery, dentistry or injuries.

Blood samples are then taken for the laboratory to carry out tests of blood clotting. The samples will be tested for the individual clotting factors. These tests can also be done on a sample of blood from a newborn baby's umbilical cord where the mother is a known or suspected carrier.

If other family members are at risk of having haemophilia, they should also be tested. Being diagnosed as early as possible means that healthcare, including surgery, dentistry and accidents can be managed safely.

Does haemophilia change as you get older?

Clotting factor levels can change as a person gets older. In most cases, this change will not alter your diagnosis or treatment, but it is important to come to your review appointments so your blood tests can be repeated if needed.

You may find that haemophilia affects you in different ways at different times in your life. For example, once a young child develops their coordination and learns how to protect themselves from accidents, they should be less vulnerable to injuries.

Different activity levels, sporting choices and general fitness may also affect your experience of haemophilia. Later in life, an adult may be more likely to need dental treatment or develop other health problems that require tests or surgery. In these situations, your haemophilia has to be considered and treatment needs to be coordinated by your haemophilia specialist and any other doctors or dentists involved.

Recognising and managing bleeding

Most of the time, mild or moderate haemophilia does not interfere with everyday life and activities. There is often enough clotting factor to protect against problems with bruising and minor injuries. However, because bleeding problems do not happen often, they are unexpected and may not be quickly recognised and treated.

If you have not had a problem for months or years you, and any doctor or dentist you see, may not be aware of the risks and this is when bleeding problems can develop.

For example:

- you might forget to tell them about your haemophilia diagnosis
- they may not understand why you need treatment
- it might not be discussed with your haemophilia centre

Moderate haemophilia typically leads to bleeding problems after minor injuries including sporting injuries. If the clotting factor level is towards the lower end of the range, bleeding may be more frequent and sometimes happen without a clear cause.

The following types of bleeding may occasionally affect you, or may never happen to you. However, there are some important steps you should take if they ever do. It is important to recognise the signs of bleeding so that you know when to get advice and treatment.

Bleeding affecting joints or muscles

Bleeding into muscles can happen after excessive stretching, a blow or a fall which causes tearing of the muscle fibres. You may notice pain, discomfort, warmth or swelling. Movement may be limited in a nearby joint because the muscle hurts if it is stretched or moved. A young child may not want to use an affected arm/leg or may be limping.

Contact your haemophilia centre:

- **immediately** if you have tingling in your toes or fingers in the affected arm/leg
- where a bruise seems to be getting bigger over a few hours, is painful, restricting movement in a nearby joint, or is near a critical place such as your eye
- if a joint is swollen or painful
- if you are unsure – because if bleeding continues, symptoms will get worse, recovery time will be longer and the risk of complications increases

Rest

Rest an injured arm or leg, as continuing to use it may make the bleeding worse. Raise the injured arm or leg above the level of your heart to slow the flow of blood to the injured area

Ice

Ice can also slow the flow of blood and help to reduce swelling, by shrinking the blood vessels. Various cool and gel packs are available and it's useful to have one in the fridge – if not, a packet of frozen peas will do. Use a cloth between an ice pack and your skin, and apply it for a maximum of 15 minutes at a time, every 1 to 2 hours.

Nosebleeds

- sit upright
- squeeze the widest part of the nostrils together for 10-15 minutes – if this does not stop the bleeding, try again for another 10-15 minutes
- put a cold cloth or cool pack on the back of your neck and on the bridge of your nose

Contact your haemophilia centre:

- if the nosebleed does not stop after you have tried the steps above

Mouth bleeds

- avoid using drinking straws
- drink cold fluids only
- eat soft food
- avoid walking around with hard or sharp objects, such as a pen or toothbrush, in your mouth

Contact your haemophilia centre:

- if mouth bleeding continues for more than 30 minutes or keeps starting again

Head injuries

A person with haemophilia who has a head injury will need immediate treatment to increase their clotting factor level because of the risk of bleeding into the brain.

Signs of a serious head injury can include any of the following:

- headache
- blurred or abnormal vision
- feeling or being sick
- stiff neck
- loss of coordination
- sleepiness
- loss of consciousness
- fitting

Minor head bumps are particularly common in toddlers and it is often difficult to decide if they need to go to the hospital. If in doubt ring the haemophilia centre for advice. If there is an obvious bruise or swelling treatment may be needed.

The haemophilia centre should be contacted:

- after any other injury
- if you have an accident that causes bleeding or needs stitches
- if there is blood in your urine
- if you notice that, when going to the toilet, your stool (poo) contains blood or is black and tar-like

Surgery

People with mild or moderate haemophilia can have any form of surgery providing they have been given the appropriate advice and treatment. **Before any operation**, the surgeon should discuss your treatment with your haemophilia specialist. If surgery is planned for you, let your haemophilia centre know as soon as possible.

This also applies to some medical investigations, such as endoscopy. It may be that some procedures that are now commonly done as day cases may result in you staying overnight in hospital. An operation may require a couple more days in hospital than usual.

Dentistry

Good dental care is particularly important for people with haemophilia. Regular check-ups and dental hygiene will help stop problems developing. Continuous gum bleeding is a sign of gum disease, not haemophilia, so speak to your dentist and hygienist.

Most routine dental care can be carried out by your local dentist, but it is important that they know you have haemophilia. Some dental work may need treatment to avoid bleeding and this will be co-ordinated by your haemophilia centre.

You should show your special medical card to any doctor or dentist you consult. Keep your card on you or carry another form of medical identification, such as a bracelet, in the event of accidents.

Women

Haemophilia carriers with lower than normal levels of clotting factor may have heavy periods. The risk of other bleeding problems will be the same as for any person with mild or moderate haemophilia and will be related to how low your clotting factor level is.

Clotting factor levels should be measured in pregnancy. Care for your pregnancy and delivery should be planned by your doctor and haemophilia centre.

Treatment

Treatment may be needed before and after dentistry or surgery to prevent bleeding. It should also be started as soon as possible after an injury. If you are bleeding, the quicker you get treatment, the sooner the bleeding will stop and recovery can begin.

Whether treatment is necessary and the type of treatment recommended will depend on the:

- type of injury and risk of bleeding
- site and amount of bleeding
- type of surgery or dental treatment
- patient's clotting factor level

Haemophilia cannot be cured but treatment allows people to enjoy a good quality of life. Clotting factor medicines are used to stop and treat prolonged bleeding. These medicines are given as an injection. In milder cases, injections are usually only given in response to prolonged bleeding.

Other medicines and vaccines

Aspirin should not be taken as it affects how platelets work. Platelets are an important part of the blood clotting system. Ibuprofen and Voltoral[®] should not be taken without advice from your haemophilia specialist as they too can affect platelet function. Some of these are now sold over the counter, so if you are unsure about what a particular medication contains, ask the pharmacist for advice.

Paracetamol and codeine preparations do not interfere with blood clotting and are therefore suitable for people with haemophilia.

Some herbal preparations can affect blood clotting in a similar way to aspirin. You should avoid the following:

- black cohosh
- pan d'arco
- ginkgo biloba
- cat's claw
- feverfew
- garlic capsules

Injections into muscles may cause bleeding and should be avoided. Immunisations should be given under the skin (subcutaneously).

As you might need blood products at some point, vaccination against Hepatitis B may be recommended by your haemophilia centre.

If you are uncertain about whether any medication may affect blood clotting, check with your haemophilia centre.

Sport

A good level of physical fitness helps reduce the risk of injuries, and sport can increase self-esteem, confidence and social skills. Most sports are suitable for people with mild or moderate haemophilia. However, contact sports carry risks of head, neck and joint injuries which may cause serious bleeding problems. It may take longer to recover from any sporting injury, particularly if treatment has been delayed. Please discuss choices of sport with the haemophilia team.

Holidays

Discuss your travel plans with haemophilia centre staff at least two weeks beforehand and find out if there is a haemophilia centre near where you will be staying.

Depending on where you are travelling, you may need to take a small supply of treatment with you in case it is not available at a local hospital. If you are travelling abroad, your haemophilia centre will provide you with a letter for customs in case you are asked to explain the treatment. Keep the treatment in your hand luggage rather than checking it in – you have less chance of losing it and the hold has more extreme temperatures.

The Haemophilia Society can advise you on suitable travel insurance policies:

www.haemophilia.org.uk

Telephone: 020 7939 0780

Email: info@haemophilia.org.uk

Who should be told about your haemophilia?

- Your GP and dentist
- Any other doctor you see
- Any pharmacist you ask for advice
- Your employer. Some people choose not to tell their employer. Others do and find it helpful for them to know in case they need time off work for a bleeding problem. Accidents at work should be handled with standard first aid.

How to contact your haemophilia centre

If you have any questions about mild or moderate haemophilia please ask a nurse or doctor.

Haemophilia centre

Second floor, Garry Weston Centre

Hammersmith Hospital

Du Cane Road

London W12 0HS

Telephone: (haemophilia nurses) 020 3313 4345 (09.00 – 17.00, Monday to Friday)

It is important to know your contact numbers for the haemophilia centre and 'on-call' night and weekend arrangements. Out of hours contact the 24-hour helpline on: 020 3311 7755

How do I make a comment about my visit?

We aim to provide the best possible service and staff will be happy to answer any of the questions you may have. If you have any **suggestions** or **comments** about your visit, please either speak to a member of staff or contact the patient advice and liaison service (**PALS**) on **020 3313 0088** (Charing Cross, Hammersmith and Queen Charlotte's & Chelsea hospitals), or **020 3312 7777** (St Mary's and Western Eye hospitals). You can also email PALS at **imperial.pals@nhs.net**. The PALS team will listen to your concerns, suggestions or queries and is often able to help solve problems on your behalf.

Alternatively, you may wish to complain by contacting our complaints department:

Complaints department

Fourth floor

Salton House

St Mary's Hospital

Praed Street

London W2 1NY

Email: **ICHC-tr.Complaints@nhs.net**

Telephone: **020 3312 1337 / 1349**

Alternative formats

This leaflet can be provided on request in large print or easy read, as a sound recording, in Braille or in alternative languages. Please email the communications team:
imperial.patient.information@nhs.net

Wi-fi

We have a free wi-fi service for basic filtered browsing and a premium wi-fi service (requiring payment) at each of our five hospitals. Look for WiFiSPARK_FREE or WiFiSPARK_PREMIUM