

Mild and Moderate Haemophilia and the Transition to Adult Services

Information for
patients



This leaflet is for patients with **mild** and **moderate** Haemophilia A and B who are aged 16 or over and is ready to be transitioned to the **Adult Haemophilia Team**.

What is Haemophilia?

Haemophilia A is a condition caused by the body lacking a clotting factor called Factor Eight (written as VIII).

Haemophilia B is a condition caused by the body lacking a clotting factor called Factor Nine (written as IX).

Normal Concentration Factor VIII + Factor IX	50-150 per decilitre of blood
Mild Haemophilia	5 - 30
Moderate Haemophilia	1-5
Severe Haemophilia	Less than 1

Mild and Moderate Haemophilia occurs when these clotting factors levels are reduced. This means that those affected may have symptoms of bleeding, for example;

- **Bad bruising from minor trauma**
- **Prolonged nose bleeds**
- **Excessive bleeding from minor cuts**
- **Bleeding gums**
- **Rarely, severe internal bleeding inside the body or joints may occur after significant trauma**

These symptoms can vary significantly but the majority of patients with mild and moderate haemophilia do not experience problems with bleeding from day to day. However, it is important to remember even if you do not have any symptoms of bleeding, if you have a planned intervention such as dental surgery you must inform your dentist and contact the haemophilia team who will be able to advise you. Any dental treatment or surgery should take place at the Dental Institute in Leeds.

If you are involved in an accident or injure yourself you should also notify the Accident and Emergency staff that you have haemophilia and show them your bleeding disorder card.

It is also important that you **DO NOT TAKE Non Steroidal Anti Inflammatory Drugs NSAID's** (pronounced en-said) as they can cause bleeding into the stomach.

NSAID's include:

Ibuprofen, nurofen diclofenac potassium, diclofenac sodium, aceclofenac, acemetacin, celecoxib, dexibuprofen, dexketoprofen, etodolac, etoricoxib, felbinac, fenoprofen, fluribiprofen, indometacin, ketoprofen, mefenamic acid.

We don't expect you to remember the list! Just remember **NSAID's**. If you are prescribed them it must be under the supervision of your haematologist.

When you are prescribed or buy drugs over the counter always inform your doctor or pharmacist about your haemophilia diagnosis and **show them your bleeding disorder card**.

When you are asked - 'Do you have any allergies?'

Your response should be - 'I have haemophilia so cannot take NSAID's.'

Treatments for Haemophilia A and B

Tranexamic Acid - is a medicine that controls bleeding. It helps to stop blood clots from breaking down, which slows down bleeding. It is used for nose and gum bleeds and also bruising. It is often prescribed for dental procedures and is used as a mouth wash and then the solution is swallowed.

Desmopressin (DDAVP) - (Can only be used if you have mild Haemophilia A) Desmopressin is a synthetic hormone. It works by stimulating the production of clotting factor VIII (8). Raising the factor VIII (8) level will help to make your blood clot.

You are likely to have had a desmopressin trial when you were younger to see if this treatment is effective as it does not work for everyone. The medicine is usually given as an injection under the skin but can also be given into the vein or as a nasal spray. It is often used to prevent bleeding during minor procedures such as dental treatments and also for nose bleeds.

Factor Concentrates - Factor VIII (8) concentrates are used to treat Haemophilia A and Factor IX (9) concentrates are used to treat Haemophilia B. These are given into a vein and will increase your Factor VIII (8) or Factor IX (9) levels and are used to treat more serious bleeding or if desmopressin cannot be used.

Why do I have Haemophilia ?

Haemophilia is primarily a genetic disorder; over two thirds of patients affected will have a family member who has haemophilia. For one third of patients however, the gene will have occurred spontaneously with no family history of the disease.

Haemophilia A and B only affects males. However, female carriers (those who carry the gene and have male relatives affected) occasionally have signs of a mild bleeding disorder. If you have a female relative who wants to start a family please speak to your consultant or nurse.

If you would like more information about haemophilia a good resource is The Haemophilia Society website:

www.haemophilia.org.uk

Transition to Adult Services

While you have been cared for by the children's services, in general your parents or guardians would have taken charge of your care.

Around 16 years of age, patients who have been under the care of the children's services must be transferred to the adult service. This is important as your needs will have changed from when you were younger. As a child your care was provided with a child/family centred approach but as you get older and are making independent life choices it is important that the responsibility for managing your haemophilia shifts to you as an individual. You should have been prepared for this process by becoming part of the decisions made about your care and being actively involved in consultations.

Now you are old enough to transition to adult services you are expected to be in charge of your care. However, you will always have the support of your haemophilia nurses and doctors at the hospital.

In due course, you might be thinking about career choices, moving out of the family home and eventually starting a family of your own. The adult haemophilia team will be able to help you with any queries you may have about your diagnosis and how this will affect your future.

It is likely that previously you will have had yearly telephone reviews if your symptoms were mild and well managed; it may have been that your parent or guardian undertook these consultations for you. However, for your first appointment in adult services it will be a face to face appointment. This is important so that you can meet the staff involved in your care and familiarise yourself with Bexley Wing at St James Hospital in case you need to attend for treatment or emergency review. After this initial appointment it is likely that you will be reviewed by telephone every 6 - 12 months.

You are still a patient of the children's team UNTIL you have had your first appointment with your new adult haematologist. Before this appointment, if you have a problem or query you can direct it to the children's team.

To contact the children's team call

0113 392 7179 - For appointments

0113 392 6863

For advice - Haemophilia Nurse Specialist - Ruth Hughes

The Adult Haemophilia Centre is on Level 3 at Bexley Wing, St James University Hospital. There are several bus routes that take you there from Leeds city centre and there is a multi-storey car park on site.

To contact the adult team call

0113 206 8458 - For appointments

0113 206 8321

For advice - Haemophilia Nurse Specialists - Emma Carter, Charlotte O'Brien, Laura Hatton

Out of hours contact

Inpatient wards 88-89

0113 206 9188 or 0113 206 9189

For contact information in an emergency refer to your **bleeding disorder card**.



What did you think of your care?

Scan the QR code or visit bit.ly/nhsleedsfft

Your views matter



© The Leeds Teaching Hospitals NHS Trust • 1st edition (Ver 2.0)
Developed by: Helen Turner and Ruth Hughes Clinical Nurse Specialists.
Produced by: Medical Illustration Services • MID code: 20210226_001/RC

LN004892
Publication date
07/2020
Review date
07/2023