- Trouble sleeping if taken too late in the day,
- Change in mood,
- Increased appetite and weight gain
- Diabetes
- High blood pressure
- Increased risk of infection

The nurse caring for you can explain this in more detail. You will be also given some medication to try offset some of these complications

- Osteoporosis
- Stomach Ulcers

Rituximab

Rituximab is a drug that works specifically by attaching itself to the cells that are producing the antibodies which are destroying the Factor VIII.

Usually 4 treatments are given into a vein over a 4-week period.

In some incidences, Rituximab may cause an allergic reaction while it's being given. This is more common with the first treatment, so it will be given slowly over a few hours. The nurse will give you drugs to help prevent or reduce this.

In the event that you do have a reaction the nurse will administer medication promptly to reverse this.

Signs of a reaction can include:

- Feeling unwell or different to before infusion started
- Shortness of breath
- Pain in your back, tummy or chest
- Tickle in your throat
- Flu-like symptoms (headaches, a high temperature or chills)
- Feeling sick
- Rash
- Feeling itchy

It is very important that you tell your nurse straight away if you have any of these symptoms.

You may be on one or all of the above treatments above when diagnosed with acquired haemophilia.

What to do when you are discharged

You will be under regular follow up from the NCC medical team initially. Contact the NCC if you have any signs of bleeding. Signs of bleeding include bruising, blood in the urine, blood from the back passage, pain, swelling or loss of movement of limbs.

If you need any invasive procedures or dental work, please contact the National Coagulation Centre for advice beforehand. It is important to note that injections in to your muscles (IM) are not advised, unless advice is sought from your haemophilia doctor or nurse. You should also avoid NSAIDS (Aspirin/Ibuprofen/similar drugs)

CONTACT DETAILS

Emergency Contact Details

Monday to Friday 08:00-17:00

For Emergency/ urgent calls in relation to an active bleed or possible bleed or an urgent unplanned procedure please call:

01-4103000 and ask for the nurse on bleep 721.

'Out of Hours' service for patients with a registered bleeding disorder:

After 17:00 hours on weekdays, at weekends and on bank holidays please contact the H&H inpatient Ward on 014103132 where a nurse will carry out a telephone triage, the nurse will assess if you need to attend the H&H assessment unit, your local emergency department or SJH Emergency Department. The nurse will inform the Haematology SHO 'on- call' of your attendance. A review will be done as soon as possible upon arrival to SJH. Please always carry your Bleeding Disorder ID Card in case of emergency.

Non Urgent Clinical Queries

For non-urgent, clinical queries in relation to upcoming procedures, treatment queries…

Monday-Friday 08:00-17:00 Please call 01-4103130 (please leave a message with your name, hospital number, contact details and information in relation to your query and a nurse will return your call)

Acquired Haemophilia

Patient Information Leaflet

This leaflet has been designed to provide information and advice to people and their families who have been diagnosed with Acquired Haemophilia.

The information is a guide only and specific questions can be answered by your doctor or nurse specialist in the National Coagulation Centre (NCC), St James's Hospital.

What is Acquired Haemophilia?

Haemophilia describes a group of blood disorders in which there is a problem with clotting of the blood. Blood contains proteins called clotting factors, and these work to stop bleeding. The lack of clotting factor causes people with haemophilia to bleed for longer periods of time than people who have normal blood clotting levels.
The most common form of haemophilia is inherited and a person who is born with haemophilia will have it for life.

However, a much rarer form of haemophilia exists called **Acquired Haemophilia** and people with this type of haemophilia are not born with it but develop the condition later in life. This type of haemophilia usually affects the clotting factor VIII (eight).
In acquired haemophilia, the gene for factor VIII (eight) is normal. Instead the person's own immune system starts to destroy their own Factor VIII as fast as it is made. It affects men and women equally and can present at any age, however acquired haemophilia is more likely to develop in older people.

How is it diagnosed?

Usually, the first sign is significant bruising on the body; often the bleeding is spontaneous and not associated with knocks or injuries.
The bleeding can occur in the muscles; this can be very painful and cause loss of movement.
Other times, it can result in excessive bleeding following a surgical procedure, blood in the urine or from the bowels.
A simple blood test that looks at the body's clotting system will identify that it is not working; extensive tests are then carried out by a specialist lab like the one here in St James's hospital.

Is it Serious?

Acquired haemophilia can cause serious life-threatening bleeding. However, once it is diagnosed a number of treatments are available.

What causes it?

In many cases the cause is unknown; part of the immune system just stops working correctly. The body's immune system sees its own Factor VIII as foreign and produces antibodies which destroy the factor VIII.
In some cases, it can be associated with another illness, e.g. rheumatoid arthritis, ulcerative colitis, asthma, psoriasis, cancer and it can develop in women who have just had a baby.

Acquired haemophilia is a very rare condition and is usually managed in a specialist haemophilia centre like the National

Treatment

There are two main goals in the management of acquired haemophilia: 1) Manage and treat bleeding. 2) Suppress the immune system to stop the destruction of factor VIII. You will be advised to stay in hospital until your factor levels return to safe levels. This normally takes many weeks; however individual patient response times vary so we cannot provide a specific time frame.
Clotting factor concentrates (CFC) are given to treat bleeding and steroids and/or Rituximab are given to suppress the immune system.

Clotting Factor Concentrates (CFC)

CFCs are given to treat bleeding. This involves injecting clotting factors directly in to your blood stream through your vein. These treatments may have to be given several times a day initially by the doctors or nurses.
There are several types of clotting factors used; some come from blood plasma donated from other people; others are developed in labs and these are called recombinant products. While the CFCs are useful to control bleeding, they do not treat the antibodies being made by the immune system and therefore, other treatments which control the immune system are also needed (steroids and Rituximab – see below).

Steroids

Steroids are used in high doses initially to suppress the immune system and stop the body producing the antibodies that are destroying the factor VIII. In Acquired Haemophilia, steroid treatment is often needed for several weeks at high dose and once the factor levels return to normal, steroids are slowly reduced over a number of weeks.
Steroids are very effective drugs but sometimes have side effects, these include: