

Factor level testing

Factor level tests measure how much clotting factor VIII (8) or IX (9) the body is producing.

This will help to understand whether you or your daughter are likely to have abnormal bleeding and will need a treatment plan.



When to have factor level testing over a lifetime

It is recommended that girls and women have clotting factor level testing if they:

- Are haemophilia carriers
- Are likely to be carriers because of their family's history of haemophilia
- Prior to any surgery if they are a carrier or possible carrier
- Have bleeding symptoms that suggest low factor levels.⁵

Girls or women should have factor level testing at least once, preferably as soon as a girl shows bleeding symptoms or before she starts menstruating.

Testing may need to be repeated over her lifetime: her factor levels may change with pregnancy and hormonal medications such as the contraceptive pill and as she grows older.

Testing a fetus or newborn baby?

It is not recommended to do fetal blood sampling for factor levels. This is a complex procedure where blood from the fetus (unborn baby) is taken while it is still in the mother's uterus (womb) and has significant risks for the fetus.



It is generally not recommended to do routine umbilical cord blood testing or newborn tests on a female baby for factor levels. Newborn factor level testing can be challenging and in some situations factor levels can change in the first weeks or months before they settle to the level they will be in the long-term.

When symptoms appear

Testing factor levels is important if a female baby, girl or woman has abnormal bruising and bleeding that suggests haemophilia, including heavy periods, oozing or bleeding for a long time after cuts or losing teeth, or nose bleeding that lasts for 10 minutes or longer in spite of constant pressure.



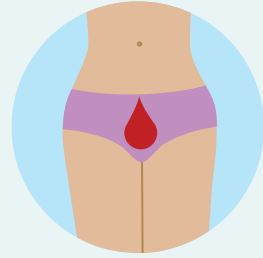


Before starting periods (menstruation)

If haemophilia is a possibility, a girl should have factor level testing before she starts menstruating (getting her period).

Testing before periods start helps a girl and her parents to be prepared and well-informed.

A treatment plan can be developed to manage heavy periods.



Surgery, medical procedures or dentistry

Factor level testing is essential if you are having planned surgery or medical or dental procedures that pierce the skin, no matter how minor.

You may need a management plan from your Haemophilia Treatment Centre so that the procedure can proceed safely.

Vaccinations generally do not cause a problem when constant pressure is applied for a 2-5 minutes after the injection.

Pregnancy

Factor level testing is particularly important **before** you become pregnant, or as soon as possible if you did not plan the pregnancy. This is to manage any potential bleeding throughout pregnancy and childbirth:

- with invasive procedures where there is a risk of bleeding, such as in procedures with IVF (in vitro fertilisation) and prenatal diagnostic testing of the fetus
- preparing for bleeding risks during childbirth and after delivery.



Other times?

Talk to your haemophilia team about other times you might need to have your clotting factor level done again.

Who arranges a factor level test?

Ask your haematologist (doctor specialising in blood disorders) or Haemophilia Treatment Centre (HTC) about factor level testing. They will advise you and can arrange testing.

If you or your daughter are not registered with a Haemophilia Treatment Centre, speak to your GP about a referral to an HTC. Your GP can also arrange factor level testing through a local pathology provider.





What does the factor level test involve?

“ Factor level testing is just like a normal blood test – it’s painless and quick. ”

“ The process isn’t scary. You’re fully informed by your haematology doctor and nurse about the results and what to do if the test returns positive. ”

Factor level testing is a blood test.

It can be done at the blood collection service at the same hospital as your Haemophilia Treatment Centre or you may be referred to a local pathology service. In some cases the HTC may do the blood test.

Only a small amount of blood is taken – around a teaspoon or less.

Results

Your results will be given to you by the haematologist or the nurse practitioner at the Haemophilia Treatment Centre and they will explain what the results mean.

The way results are reported may vary depending on the laboratory and your Treatment Centre will need to interpret this for you.

Factor levels and severity

The normal level of factor VIII or IX in a person's blood is between 50% and 150%

Severity and factor level	What to expect if you are female
<p>Mild haemophilia 5 – 40% of normal clotting factor</p>	<ul style="list-style-type: none"> • Likely to bruise easily and have prolonged bleeding after minor cuts • Likely to have bleeding problems after a bad injury, tooth extractions, surgery or medical procedures that pierce the skin • May have heavy menstrual bleeding (heavy periods) • Might have bleeding problems with childbirth • Other than periods, might only have bleeding problems requiring medical attention very occasionally
<p>Moderate haemophilia 1 – 5% of normal clotting factor</p>	<ul style="list-style-type: none"> • Likely to bruise easily and have prolonged bleeding after minor cuts • Likely to have bleeding problems after a bad injury, tooth extractions, surgery or medical procedures that pierce the skin • Likely to have heavy menstrual bleeding (heavy periods) • Sometimes have bleeding problems with childbirth • Might have bleeding problems with minor injuries, such as sporting injuries • Occasionally have a bleeding episode for no obvious reason ('spontaneous bleeds')
<p>Severe haemophilia Less than 1% of normal clotting factor</p>	<ul style="list-style-type: none"> • Likely to bruise easily and have prolonged bleeding after minor cuts • Likely to have heavy menstrual bleeding (heavy periods) • Likely to have bleeding problems with childbirth • Often have bleeding into joints, muscles and soft tissues • Can have bleeding episodes for no obvious reason ('spontaneous bleeds') as well as after surgery, dental work or injuries including minor bumps and knocks.



Women and girls can have a range of symptoms with haemophilia.

“ As long as I can remember, I was told that I was a carrier. My older brother didn't have haemophilia. We wrestled, rode our bikes, fought and were just kids that loved to play outside. And yes, very often I would end up covered in bruises from head to toe!! ”

“ I mainly experience bleeding issues during dental surgery - excessive bleeding, swelling and bruising. I also had marginally heavier bleeding after childbirth than is considered normal. Occasionally I come up with bruises and I'm not sure why! ”
But on a daily basis, haemophilia doesn't affect my life.

“ I am a female with mild haemophilia A. I was only diagnosed following my son's diagnosis. If I hadn't been tested, I would never have known I was a carrier and had the condition. I get very heavy periods but I didn't think anything of it and once I had very minor surgery with an internal bleed afterwards. They were the only occasions where I have been affected. ”

