NHS
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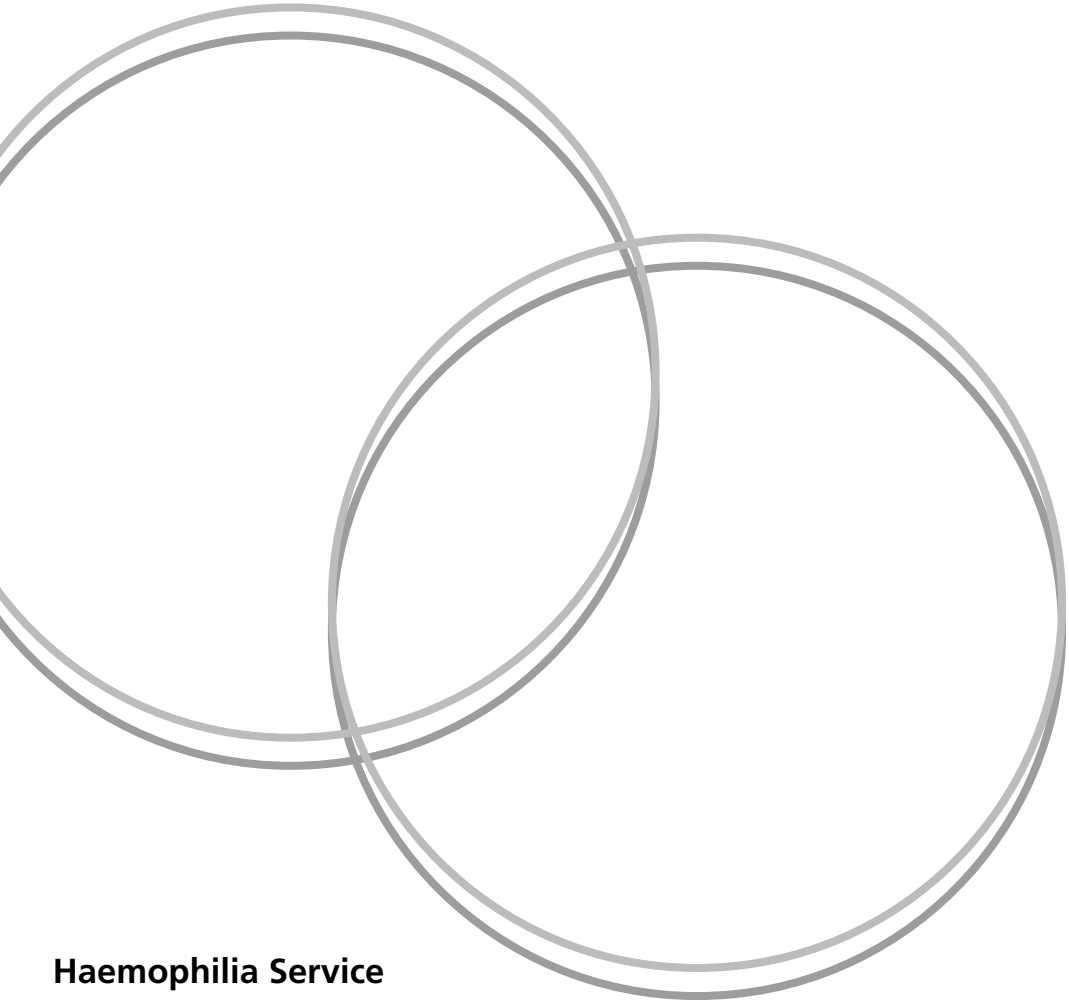
Information about Pregnancy for Haemophilia Carriers



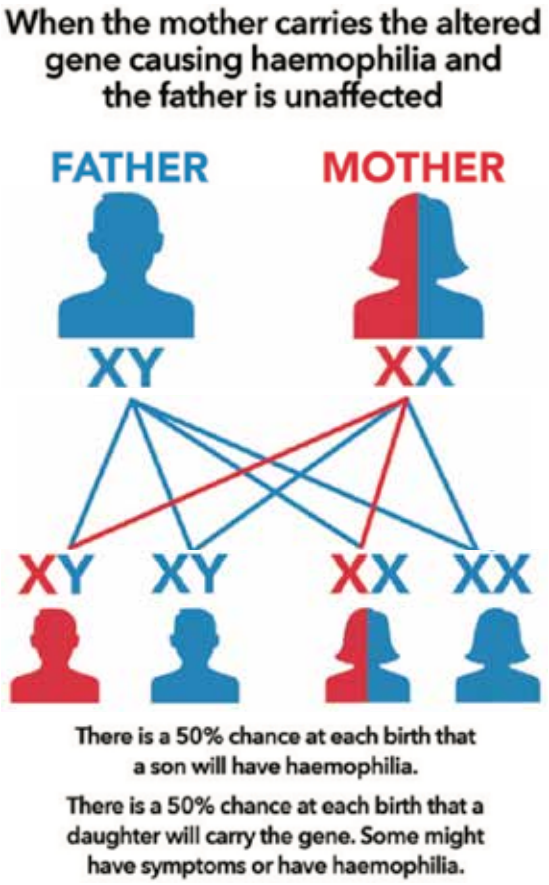
Haemophilia Service

If you are a carrier for haemophilia A or B and are thinking of having a baby, it is important that you are looked after by the Adult Haemophilia Service.

Haemophilia is an inherited disease. It is passed on the X chromosome on a specific gene from the parent to their child.

There are two forms of haemophilia: haemophilia A and haemophilia B. These are both caused by the lack of a clotting factor, factor VIII (8) or factor IX (9). As haemophilia is an X chromosome linked disease it usually only affects males. For more information about this, please ask for our 'Carriers of Haemophilia' leaflet.

The following diagram explains how, as a carrier of haemophilia, the altered gene may affect your child.



Source: Haemophilia Foundation Australia (www.haemophilia.org.au), 2017

During pregnancy

As a carrier of haemophilia, you may already have low factor VIII or factor IX levels, which can increase your risk of bleeding.

If you are a carrier of haemophilia A, your levels of factor VIII are likely to rise significantly during pregnancy. If you are a carrier of haemophilia B your factor IX levels are not likely to change much during pregnancy.

To work out your risk of bleeding, particularly during the delivery of your baby, it is important that we check your clotting factor levels at least twice during your pregnancy. This is usually done in the first trimester (first 3 months of pregnancy) and then again at 32-34 weeks.

Prenatal diagnosis

A prenatal diagnosis is a group of tests that can be used for women and couples who are at risk of having children affected with inherited conditions, such as haemophilia.

Prenatal diagnosis can be used for two main purposes; to guide whether to continue a pregnancy, or to guide doctors in how best to deliver the baby.

It is best to have a discussion about prenatal diagnosis before becoming pregnant, so that you can be informed of all possible options available before starting a family.

Testing

There are several tests available.

Maternal blood testing

Recent advances in genetic testing allow us to test the sex of your unborn baby in the first trimester. This is known as free foetal DNA (ffDNA) testing and is carried out using a small sample of your blood. As this test only involves collecting a 20ml sample of your blood there is no risk to you or your baby.

Cells from your baby (foetus cells) can be detected in your blood from early in pregnancy. These cells can be analysed, to work out the sex of the baby. The laboratory will look for the presence of the Y chromosome, to find out whether you are carrying a male baby.

This test is ideally carried out at 8-9 weeks gestation. It is 99% accurate, but occasionally there is not enough presence of the Y chromosome to be able to accurately confirm the sex of the baby. This mainly happens if the test is carried out too early in the pregnancy, so you will have a dating ultrasound scan before having the test.

This test is not routinely offered unless you are considering whether to continue the pregnancy.

Chorion villus sampling (CVS)

If the ffDNA result shows that you are having a boy then there are further testing options available to find out if your baby is affected with haemophilia.

CVS has a chance of causing a miscarriage. We estimate this risk to be about 1 in 100. A miscarriage may occur up to 3 weeks after the CVS. We cannot predict which pregnancies will miscarry. CVS is carried out early in pregnancy, when miscarriages are slightly more common.

If you are still considering whether to continue with the pregnancy, CVS can be carried out. For more information, please ask to see our 'Chromosome and genetic testing in pregnancy' leaflet.

The CVS sample goes through DNA analysis to find out whether the baby is affected with haemophilia. The results take 5 working days to return.

If you have a low clotting factor level you may need to receive treatment before having the CVS.

20 week scan

If you haven't yet found out the sex of your baby you will be encouraged to do this at the 20 week scan.

It is highly recommended that you find out the sex of your baby, because it allows the Haemophilia team and your maternity doctor (obstetrician) to plan your baby's delivery safely.

The sex of your baby can influence decisions about how we care for both you and your baby during delivery. If you are carrying a baby boy who may be affected with haemophilia then we will need to take safety precautions and put a management plan in place.

If you are carrying a baby girl she will be unlikely to have a very low factor level, so fewer safety precautions will need to be taken at the time of delivery.

If you do not want to find out the sex of your baby, please tell us, as we will still need to discuss plans to deliver your baby safely.

Third trimester amniocentesis

An amniocentesis, where a small sample of the fluid that surrounds your baby is collected, may be offered between 34-36 weeks gestation. This can be used to find out whether a male baby is affected with haemophilia. This will help your obstetrician and the Haemophilia team to make decisions about where and how your baby should be delivered.

The risks of third trimester amniocentesis include a 1 in 200 risk of premature rupture of amniotic membranes (breaking of the membrane which surrounds the baby) and a small risk of introducing infection into the amniotic fluid (often referred to as 'the waters').

It takes 5 working days to get the results of the amniocentesis. If the amniotic membranes are prematurely ruptured, the results may not be available to help plan your delivery (as you may go into labour immediately). 1 in 10 tests will not give a result.

For more information, please ask to see our 'Chromosome and genetic testing in pregnancy' leaflet.

What happens if my baby is affected by haemophilia?

If your baby is affected with haemophilia, you will be advised to give birth at the Oxford University Hospitals Women's Centre, under the care of the Silver Star team (the high risk pregnancy service).

This will mean we can make sure specific safety measures are in place, such as making sure foetal scalp electrodes aren't used (for monitoring the baby's heartbeat) and an instrumental delivery is avoided (where forceps or a vacuum extraction are used to help your baby to be delivered). These all have a risk of causing your baby bruising and bleeding.

If your baby is not affected with haemophilia you may be able to deliver at your local Maternity unit.

Other tests

Before invasive procedures, such as CVS or a late amniocentesis, it is important that you have tests to check your factor levels. This is to see whether you need any factor therapy to reduce your bleeding risk during the procedures.

How to contact us

If you would like further advice or have any other questions, please telephone the Adult Haemophilia and Thrombosis Centre.

Tel: **01865 225 316**
(9.00am to 5.00pm, Monday to Friday)

For emergency advice outside office hours, at weekends and on Bank holidays, please telephone the Oxford University Hospitals switchboard: **0300 304 7777**

Ask to speak to the 'on-call Specialist Registrar for Haematology'.

Children's Haemophilia and Thrombosis Centre

Tel: **01865 226 562**
(9.00am to 5.00pm, Monday to Friday)

If you need an interpreter or would like this information leaflet in another format, such as Easy Read, large print, Braille, audio, electronically or another language, please speak to the department where you are being seen. You will find their contact details on your appointment letter.

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