

## **Screening for Down's syndrome, Edwards' syndrome and Patau's syndrome**

An **easy guide** to screening tests when you are pregnant

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### **Your choice**

This booklet has information about tests you can have. The tests can find things early but they may not find everything. The tests can tell us more about your baby and we can give you information or tell you about treatment for you or your baby.

The tests can show if your baby may have Down's syndrome, Edwards' syndrome or Patau's syndrome.

You can choose if you want to have the tests.

The tests can help you make choices about your care when you are pregnant. If you are worried, you can talk to your midwife or doctor.

### **About these tests**

We only show the results of the tests to health staff who need to see them.

It is important to tell your midwife about any health problems you have.

It is rare for a baby to have Down's syndrome.

It is very rare for a baby to have Edwards' syndrome or Patau's syndrome.

If you are between 11 and 14 weeks pregnant, you can have a test for all three conditions. You can have this test if you are having one baby or twins.

If you are between 15 and 18 weeks pregnant, you can have a test for Down's syndrome **but not** Edwards' syndrome and Patau's syndrome. You can only have this test if you are having one baby. You cannot have this test if you are having twins.

There are two parts to the test.

1. We scan your tummy.
2. We take a small bit of your blood from your arm.

These tests do not hurt your baby.

These two tests can find out if there is a chance your baby will have:

- Down's syndrome, or
- Edwards' syndrome or Patau's syndrome.

The tests cannot tell for sure if your baby will have one of the conditions. The tests can only tell if there is a higher chance or a lower chance.

## **Down's syndrome**

A baby born with Down's syndrome will have learning disabilities. This means they will find it harder to understand and to learn new things. We cannot know how much of a learning disability they will have.

Most children with Down's syndrome will go to their local primary school. Many people with Down's syndrome have jobs and can live on their own.

People with Down's syndrome sometimes have other health problems. Some of these problems may be serious.

## **Edwards' syndrome and Patau's syndrome**

Most babies with Edwards' syndrome or Patau's syndrome die before they are born or soon after they are born. Very few live to be adults.

All babies with Edwards' syndrome or Patau's syndrome have a lot of very serious health problems.

## **Test results**

If your baby has a higher chance of having one of these conditions, someone will contact you within five working days of your tests being taken.

If your baby has a lower chance of having one of these conditions, the midwife will tell you the next time you see her.

If there is a higher chance that your baby has one of the three conditions, and you are having one baby or twins, we can give you another test called non-invasive prenatal testing (NIPT).

We take a small bit of your blood from your arm. This test does not hurt your baby.

You will get the result of the NIPT in about two weeks. The result will tell you if:

- we don't think that your baby has one of the conditions, or
- there is a high chance of your baby having one of the conditions.

If there is a higher chance on the screening test that your baby has one of these conditions, or if the NIPT shows there is a high chance, we can give you another test, called an invasive test.

The invasive test has a small chance of about 1 in 200 of making you miscarry. If you miscarry, your baby will not live. You will be able to talk about the test with a midwife.

You can say no to this test.

If there is a higher chance that your baby has one of these conditions and you are between 11 and 14 weeks pregnant, you can have a chorionic villus sampling test. This is sometimes called a CVS test.

This means that a very thin needle is put into your tummy. This takes away a tiny bit of the placenta. The placenta links you to your baby. We can test this for the conditions.

If there is a higher chance that your baby has one of these conditions and you are 15 weeks or more pregnant, you can have an amniocentesis.

If you have an amniocentesis, a very thin needle is put into your tummy. This takes a tiny bit of fluid from around your baby. This can be tested for the conditions.

Only a small number of babies have one of these conditions.

Some women who are told that their baby has one of these conditions decide to carry on with the pregnancy.

Some women who are told that their baby has one of these conditions may choose to end the pregnancy. They have an abortion. This means the baby does not live.

If your baby has Down's syndrome or Edwards' syndrome or Patau's syndrome we will support you to decide whether to carry on with your pregnancy or end the pregnancy. This is your decision and support will be offered afterwards.

It is important to tell your midwife if you move home.

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