

Sgrinio Cyn Geni Cymru
Antenatal Screening Wales

Screening for Down's syndrome in pregnancy

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This leaflet explains the tests that can be done during pregnancy to find out if your baby has Down's syndrome. Women who find out that their baby has a higher chance of Down's syndrome can have a diagnostic test. This test is called amniocentesis. You can choose whether or not to have this test.



What is Down's syndrome?

Down's syndrome is a genetic condition caused by an extra chromosome. A person with Down's syndrome has 47 chromosomes instead of the usual 46.

People with Down's syndrome are affected in different ways. All have some learning disability. For some people this is mild, for others it is more severe. Most can lead nearly independent adult lives, but some need more support than others. Some also have medical conditions, such as heart problems. Many of these conditions can be treated.

What are my chances of having a baby with Down's syndrome?

Down's syndrome happens in about 1 in 500 pregnancies. It does not usually run in families. All women have a chance of having a baby with Down's syndrome. The chance increases as you get older but babies are also born with Down's syndrome to younger women. For this reason, women of all ages are offered the screening test.

The result of the screening test will tell you your chance of having a baby with Down's syndrome in this pregnancy.

What will the screening test result tell me?

There are a number of screening tests for Down's syndrome. None of these tests show definitely whether a baby has Down's syndrome or not. They show what chance you have of your baby having Down's syndrome.

The screening test does not pick up all babies affected by Down's syndrome. On average, for every 10 babies with Down's syndrome, only seven will be picked up by screening. This means three out of every 10 babies with Down's syndrome will be missed.

Does screening for Down's syndrome have any risks?

Screening is a simple blood test. The only risk would be the same as having any blood test.

What are the advantages of having screening for Down's syndrome?

If your baby has Down's syndrome, you can decide whether to continue with the pregnancy or not.

What are the disadvantages of having screening for Down's syndrome?

Having the test may make you anxious especially if you have a

result which shows you have a higher chance of having a baby with Down's syndrome. Higher chance is how we describe your result if it is between 1 in 2 and 1 in 150. If the result is between 1 in 2 and 1 in 150, you will be offered a test to see if your baby definitely has Down's syndrome. Because the diagnostic test can cause a miscarriage, many women find this a difficult decision. Some women may wish they had not had the screening test because making this decision is difficult.

Should I have the test for Down's syndrome?

Only you can decide whether to have the test or not. Some women want to find out if their baby has Down's syndrome, and some don't. All hospitals in Wales offer women a screening test for Down's syndrome but the decision whether to have the test or not is yours. You can discuss with your midwife what you want to do. They will support you whatever you decide.

What screening test will I be offered?

You will need an ultrasound scan before a blood test. The blood test can be done from 15 weeks of pregnancy up to 18 weeks.

You cannot have the test, offered in Wales, if you are having twins or more babies.

The screening test is not usually offered after 18 weeks of pregnancy. If you are more than 18 weeks pregnant and would like to have Down's syndrome screening, you will need to discuss this with your midwife or hospital doctor (obstetrician).

Where can I have the test done?

Your midwife will tell you where the test can be done.

Results

You will usually get the result of your blood test within two weeks.

Will my results be confidential?

The NHS keeps the results of all tests confidential. Hospital policies vary on how many people have access to your test results. Your midwife will be able to explain the local arrangements to you.

How will I get the result from my screening test?

Your midwife will tell you how and when you will get the result of the test. The results are given as

either 'higher chance' or 'low chance'.

What happens if I get a low chance result?

If the result shows you have a low chance of having a baby with Down's syndrome, no more tests are offered. Please remember that having a low chance does not mean that you have **no** chance of having a baby with Down's syndrome.

What if I have a higher chance result?

If your test result shows you have a higher chance of having a baby with Down's syndrome (that is, a chance of 1 in 2 to 1 in 150), you will be offered an appointment with a midwife or doctor. They will explain your test result to you, and you can discuss whether or not you want to have a diagnostic test. You may face some difficult decisions after a diagnostic test that you need to be aware of before you are tested.

Remember that the lower the figure, the higher the chance. So, for example, 1 in 80 is a higher chance than 1 in 400.

Between 3% and 5% of women (that is, between three and five out of 100) who have the screening test have a result which shows they have a higher chance

of having a baby with Down's syndrome.

The results of the blood tests offered by the NHS in Wales are monitored.

Some women pay privately to have Down's syndrome screening. Screening done by private clinics is not monitored by the NHS. This means that your midwife will have no information about the quality and accuracy of any screening tests carried out by private clinics. As with the NHS test, a private test will not be able to tell you whether or not your baby has Down's syndrome.

Diagnostic test for Down's syndrome

What are diagnostic tests?

If you have a higher chance of having a baby with Down's syndrome, you will be offered a diagnostic test.

This leaflet gives some basic information about the diagnostic test you could be offered if you have the screening test.

What is amniocentesis?

An amniocentesis is a procedure to remove about 15 to 20 millilitres (that is, three to four teaspoons) of amniotic fluid from

around the baby in the womb. The cells from your baby that are floating in this fluid can be tested in the laboratory to look at the chromosomes of the baby.

It can be done after you are 15 weeks pregnant.

Amniocentesis involves some risk. It causes a miscarriage in about 1 in 100 pregnancies (1%).

What would a diagnostic test result tell me?

The result would tell you if your baby has Down's syndrome. If the baby has Down's syndrome, you can decide whether to prepare for the birth of a baby with Down's syndrome or to end your pregnancy.

Chromosome tests can detect other chromosome abnormalities as well as Down's syndrome and if you are offered an amniocentesis, this will be explained to you.

More information

You can get more information about Down's syndrome screening from your midwife, your hospital doctor (your obstetrician), or from www.antenatalscreening.org

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