

Bloodspot tests

An **easy guide** to screening tests for your new baby

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Your choice

This booklet has information about the tests that your baby can have.

The tests can find out if your baby may have a serious health problem. The tests can show if your baby might need extra care.

These tests can find problems before you even notice them. They may not find every problem. If we find a problem early we can help your baby.

You can choose if you want your baby to have these tests. You do not have to have all these tests. You can choose which tests you want your baby to have.

We recommend that your baby has all of these tests because we may find a problem early. If we find a problem early we can help keep your baby healthy.

If you say no to the test then you can change your mind and choose for your baby to have the tests later if you want to.

Your baby can have most of the tests up to 1 year old.

But the test for cystic fibrosis has to be done before your baby is 8 weeks old.

If you are worried, you can talk to your midwife or doctor. They can help you decide if you want your baby to have these tests.

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 or health visitor about any health problems you and your baby's father have, as your baby may have them too.

The bloodspot tests look for rare and serious illnesses. Finding these illnesses early means we can help babies stay healthy.

When your baby is 5 days old health staff will prick his or her heel. They will collect some drops of blood on a card. Before the test, make sure your baby is warm and comfy. Feed your baby and cuddle them. Your baby may feel a little pain when the heel prick is done.

Sometimes we need to do another bloodspot test later on. This does not mean there is anything wrong with your baby.

Sickle cell disease

Very few babies in Wales have sickle cell disease. Sickle cell disease is a very serious blood illness. You can get it from your parents. If you get it from your parents you then have it for life.

Sickle cell disease can give you anaemia. This means you do not get enough oxygen in your blood. This makes you pale, very tired and weak.

Sickle cell disease can give you very bad pain and very serious illnesses. Babies with sickle cell disease can have medicines soon after they are born. Medicines will help them stay healthy.

Cystic fibrosis

Cystic fibrosis is also called CF. Very few babies in Wales have cystic fibrosis. Cystic fibrosis affects the baby's lungs and tummy. Cystic fibrosis fills up the lungs and tummy with sticky fluid.

Babies with cystic fibrosis can be given special food, medicines and physiotherapy. Physiotherapy is a type of treatment that helps to clear the lungs of sticky fluid. The medicine and physiotherapy help babies to be healthy and live longer.

Congenital hypothyroidism

Congenital hypothyroidism is also called CHT. Babies with congenital hypothyroidism do not have enough thyroxine which is a substance that helps you grow.

Very few babies in Wales have congenital hypothyroidism. Babies with congenital hypothyroidism do not grow well. If they are not treated they may become disabled and have learning disabilities.

Babies with congenital hypothyroidism can be given medicine. This medicine can help them stay healthy.

Inherited metabolic diseases

Very few babies in Wales have an inherited metabolic disease. Babies who have an inherited metabolic disease have problems with some foods.

We test for 6 of these diseases.

If the disease is not dealt with properly your baby may become very ill or die. We can tell you what food your baby can and cannot eat to stay healthy.

Test results

You should get the results by the time your baby is 8 weeks old.

If we think there is a problem we will contact you before then. Most babies will not have these diseases.

If they do have one of these diseases, they will be sent to an expert.

Sometimes other diseases are found. These babies may need more tests.

You will be given a red book to keep a record of your baby's health checks in. Keep the red book safe. Take it with you when you see anyone about your baby's health.

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

We keep the bloodspot test cards for at least 5 years.

We may use them:

- to check the test results again
- for other tests your baby may need
- to help us make the tests better
- to help us find out how to get better health for babies – this is called research.

Research helps make the tests better. There is a small chance that the people doing the research will ask to meet you.

If you do not want to be asked please tell your midwife.

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