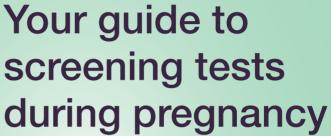
Pregnancy and newborn





2016 Edition





This resource is available in Urdu, Chinese and Polish, and in an Easy Read format.

NHS Health Scotland is happy to consider requests for other languages and formats.

Please contact 0131 314 5300 or email nhs.healthscotland-alternativeformats@nhs.net

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# Pregnancy screening tests: at a glance

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Screening involving blood test

Screening involving ultrasound scan

Remember you can discuss all screening tests with your midwife.

\* This test should ideally be carried out in the early stages of pregnancy, but it is still worth carrying out the screening tests at any point, up to and including labour.

#### About this booklet

There is a glossary at the end of this booklet. This explains the terms we usually use when providing pregnancy care, screening and diagnostic testing. Words in bold type are all in the glossary.

Please read this booklet as it will help prepare you for discussions with your **midwife** or doctor and will help you ask the questions that are important to you. It will be helpful if you have the booklet with you when you see them.

This booklet is about the **screening tests** you will be offered during your pregnancy.

Some of the tests should take place as early as possible in pregnancy – ideally by 10 weeks – but we can do them later on in pregnancy if necessary. Some other tests can only be done at a certain time during pregnancy (for example screening for Down's syndrome).

We explain what conditions can be screened for and what the screening tests involve. We also describe the follow-on steps carried out if there is a **'higher-chance' result**, and what this might mean for your pregnancy. It is important that you understand the purpose and possible results of the screening tests before you decide whether to have them.

Throughout this booklet, we use the term 'health professional taking care of you'. This is because there can be different specialists responsible for different screening tests.

# Introduction to screening and diagnostic testing

#### Being pregnant in Scotland

#### Your pregnancy care

Pregnancy care in Scotland is provided by the National Health Service (NHS). One professional takes the lead in caring for you during your pregnancy. Usually this will be a **midwife**. If you need extra care during your pregnancy, your midwife will refer you to an **obstetrician** or other professional. Options for pregnancy care vary across Scotland, but all professionals involved in your care will work in partnership with you and with each other.

Your midwife will offer you regular appointments throughout your pregnancy, but if you have any concerns or worries between appointments, phone and speak to your midwife. You can make an extra appointment with your midwife or other professional, supported by an **interpreter** if you need one.

If you would prefer to see a female health professional, please let your **GP** (General Practitioner or family doctor) or midwife know as early as possible in your pregnancy. Sometimes we may have to rearrange your appointments to make sure of this, and it may not be possible in an emergency. Almost all midwives in Scotland are female.

#### Introduction to screening and diagnostic testing

You should continue to see your GP or hospital specialist during pregnancy for medical or mental health conditions that are not related to your pregnancy. Make sure your midwife knows about these.

#### Further information about pregnancy

This booklet is about pregnancy **screening** and **diagnostic testing**.

More information can be found at www.readysteadybaby.org.uk

More information about immunisations offered during pregnancy can be found at **www.immunisationscotland.org.uk** 

A range of material in different languages about particular aspects of pregnancy is also available at: www.healthinmylanguage.com

Read Ready Steady Baby! for more information about pregnancy.



#### Your right to an interpreter

If you do not speak or understand English fluently, the NHS will provide an **interpreter** as part of your care throughout your pregnancy. An interpreter is a person who translates between two people who do not speak the same language.

You should let the professional taking care of you know beforehand that you will need an interpreter, and whether you have a preference for a female interpreter. This is because they will need time to arrange it. Depending on the area that you live in, the NHS in Scotland offers face-to-face interpreters or telephone interpreters. Interpreters must respect **confidentiality** in the same way as health professionals. This means that they cannot share information about you with anyone except authorised NHS staff.

#### Introduction to screening and diagnostic testing

#### Screening and diagnostic tests

There are two types of test:

- Screening tests are offered to all pregnant women to assess
  the chance of you or your baby having a particular health
  problem or disability. They are usually simple tests (for example,
  a blood test, ultrasound scan or questionnaire). They do not
  provide a definite diagnosis, but help you and your midwife
  decide whether you need further tests to make that diagnosis.
- Diagnostic tests are the follow-on tests that we carry out to find out whether your baby does have a particular condition. These are offered to women who have had a 'higher-chance' result from screening. This may involve chorionic villus sampling or amniocentesis (described on page 42), which can be associated with a slightly increased risk of miscarriage (described on page 43). Alternatively it may involve a detailed ultrasound scan.

These screening and diagnostic tests help to assess how likely it is that you or your baby have a condition or health problem. All tests that we offer you have been planned carefully to make sure that they are as safe and as accurate as possible. However, no test is accurate all of the time – they will not detect all cases (sometimes referred to as a **false-negative result**), and may sometimes indicate a problem even when none is present (sometimes referred to as a **false-positive result**).

#### Screening and diagnostic testing: your choice

It is your choice whether or not you accept the **screening test** we offer you, and consider follow-on **diagnostic testing** if it is indicated by the screening test. You can decide at any point that you do not want to be tested, or you can choose to have only some of the tests offered to you. The health professional taking care of you will always explain each test in detail, and will never test you without your permission.

People make different decisions about screening and diagnostic testing:

- You may choose not to be screened for any condition your baby may have, because you plan to continue with your pregnancy whether your baby is healthy or not.
- You may choose to be screened and consider diagnostic testing if it is indicated that your baby may have a health problem or disability because, although you plan to continue with your pregnancy, you would like to know whether there may be a problem with your baby so that you can prepare.
- You may choose to be screened and consider diagnostic testing
  if it is indicated that your baby may have a health problem or
  disability because you would like to know whether there may be
  a problem with you or your baby that can be treated.
- You may choose to be screened and consider diagnostic testing if it is indicated that your baby may have a health problem or disability because you want the choice of whether or not to continue your pregnancy if your baby is found to have a health problem or disability.

#### Introduction to screening and diagnostic testing

Decisions about whether to accept screening or diagnostic testing can be difficult. You may want to discuss these tests with your partner, family or friends, but the final decision about screening and diagnostic testing should be yours.

Your **midwife** can help you with these difficult decisions. You can also ask to talk with your **GP**. If the tests indicate that your baby may have a health problem or disability, you may want to talk to parents who have a child with a similar condition to find out more about it (see More information and further help – page 47). Health care and treatment for children born with health problems or disabilities is provided free on the NHS.

Whatever decision you make about screening or diagnostic testing, it will not affect in any way the quality of care that you are offered, or the attitudes of professionals caring for you. If you choose not to be tested, you will not have to explain your reasons for this.

We will not carry out any tests without your permission. We will ask you to sign a form to record that you accept or decline the different tests we offer you, and keep a record of your screening and diagnostic testing results. Only authorised staff and appropriate healthcare professionals will be allowed to see this information. All NHS staff are bound by a strict code of **confidentiality** (see glossary entry on page 53 for more information on confidentiality in the NHS).

You can find detailed information, in English and other languages, on confidentiality, consent and what happens to your health records at www.nhsinform.co.uk

#### What tests will be offered after birth?

Towards the end of your pregnancy, your **midwife** will talk to you about **screening tests** for newborn babies and you will receive another booklet, *Your guide to newborn screening tests*, which explains these in detail.

See www.readysteadybaby.org.uk for further information.

Ask your midwife for more information and a copy of the leafet *Your guide to newborn screening tests*.



### Summary of blood tests, scans and other tests offered during pregnancy

As you can see from the table near the front of this booklet, just after the contents page, we will offer you some blood tests and **ultrasound scans** during pregnancy. Some of the blood tests are to let us know about your blood type and some are for screening. Depending on the results of the screening tests we may also offer you **diagnostic testing**. These tests and scans are summarised briefly below and then described in more detail in the following sections of this leaflet.

#### Blood tests offered during pregnancy

We will offer you blood tests that tell us what your blood group is and whether you are anaemic (see page 12). We will also offer you screening blood tests for **sickle cell disorders** and **thalassaemia** (page 15), infectious diseases (page 24) and **Down's syndrome** (page 28).

#### Ultrasound scans in pregnancy

Further information about how to prepare for the ultrasound scan, and how it is performed, is provided on page 38.

We offer all pregnant women two ultrasound scans in pregnancy – an early pregnancy scan between 11 and 14 weeks and a mid-pregnancy scan between 18 and 21 weeks.

You don't have to have a scan if you don't want to. Always remember that, for most people, the scan is a happy experience. Unfortunately this is not true for everybody, which is why you

should read this information carefully and then decide whether you want a scan or not. Your choice will always be respected. Before you make up your mind there are a few things you need to know. Please read the section on page 38 carefully, where we tell you about what having a scan involves.

Whatever you decide, it will not affect the quality of care you receive.

**Early pregnancy scan**: We perform the first scan to estimate the stage of pregnancy, to assess growth and development, and to check your baby's heartbeat. This scan is sometimes referred to as a 'booking' or 'dating' scan. Very occasionally we can see some other abnormalities in your baby during this scan. If you do not want to know about these, please discuss this with your **midwife**.

If you book early enough in pregnancy we will also offer to perform a **nuchal translucency** measurement to help assess the chance that your baby has **Down's syndrome**. This is sometimes called a nuchal translucency (NT) scan, and we offer this between 11 and 14 weeks of pregnancy. This is part of the **screening test** for Down's syndrome described on page 32.

If you would like an early pregnancy scan but do not want to know your baby's chance of having Down's syndrome or other conditions, please discuss this with your midwife.

**Mid-pregnancy scan:** We offer you a second scan between 18 and 21 weeks of pregnancy. This helps us to take a very careful look at your baby (see page 34 for more information).

We will offer you further scans if there are specific indications to do so – for example, to monitor the growth of your baby, or to check the position of the **placenta**. (This is the lining of the mother's womb which links her blood supply with her unborn baby. The baby gets nourishment from the placenta.)

#### Introduction to screening and diagnostic testing

#### Diagnostic testing offered during pregnancy

These tests are offered to women who have a 'higher-chance' result from screening for **sickle cell** disorder, **thalassaemia** or Down's syndrome, and in some other circumstances.

There are two types of diagnostic screening:

Chorionic villus sampling (CVS): This can be done from 11 weeks of pregnancy and involves taking a small section from the placenta that is analysed in the laboratory. This is an invasive test that carries a small risk of **miscarriage**. See page 42 for further information.

Amniocentesis: This can be done after 15 weeks of pregnancy and involves taking a sample of fluid surrounding the baby ('amniotic fluid'). This is an invasive test that carries a small risk of miscarriage.

See page 42 for further information.



# Blood tests offered during pregnancy

We will offer you some blood tests which, together, form an important part of your care during pregnancy. They help to protect your health and the health of your baby.

Most of the tests can usually be done at one time. The **midwife** will usually take this from your arm at one of your first visits. It is your decision whether to accept these tests or not, and it won't affect the quality of your care. However, having the tests could help you make decisions about your care and the care of your baby, both before and after birth.

All results are confidential – see glossary entry for **confidentiality** on page 53 for more information on confidentiality in the NHS.



#### **Blood tests offered during pregnancy**

#### What will my blood be tested for?

#### **Full blood count**

This measures the level of haemoglobin in your blood. Haemoglobin is a part of the blood that carries oxygen around the body. If it's low, it means you could be anaemic. We may simply offer you iron tablets, or other treatments which will help your health and the health of your baby. If we find any other problems, we will offer you any further tests which may be needed.

#### **Blood group**

This shows which main blood group you belong to, either A, B, O or AB, and whether there are any blood group antibodies in your blood. Some of these antibodies can occasionally affect the baby. If this is the case we will discuss it with you. We also need to make sure that we have the correct type of blood available in case you need a blood transfusion.

The test will also show if you are **Rhesus positive** or **Rhesus negative**. About one in six women are Rhesus negative. This means that they do not have a substance called the Rhesus antigen on their red blood cells.

#### What if I'm Rhesus positive?

You will not need any treatment.

There is a glossary at the end of this booklet. This explains the terms we usually use when providing pregnancy care, screening and diagnostic testing. Words in bold type are all in the glossary.

#### What if I'm Rhesus negative?

If you are **Rhesus negative** and are carrying a **Rhesus positive** baby, problems can occur if your baby's blood enters your blood stream. This is not a problem during a first pregnancy, but can cause serious problems in future pregnancies. We will offer you an injection of **'anti-D'** which will help to protect your health and that of any future babies you may have.

#### Results of these blood tests

You will usually be able to get the results at your next clinic visit.

Occasionally technical problems can occur and we will ask you to have another sample taken.

If we find any health problems, we will contact you as soon as possible and give you advice and care. We routinely repeat some tests later in pregnancy.

### What happens to my blood samples after testing is complete?

Any of your leftover blood samples will be stored in the laboratory for at least 12 months. This is so that they can be used in the future if any test results need to be checked.

Your leftover blood samples may be used **anonymously** for other monitoring and laboratory purposes, such as comparing different screening methods and developing new tests. Sometimes leftover blood samples are also used anonymously for education and research to improve the quality of patient care.

Sometimes we may need to use samples that aren't anonymous – we will always ask for your **consent** before your samples are used in this way. If you do not want your stored blood samples to be used for research, please ask the midwife to write 'no research' in the comments box on the request form.

Screening for sickle cell and thalassaemia disorders

# Screening for sickle cell and thalassaemia disorders in early pregnancy

At or shortly after your first **midwife** visit you will be offered **screening tests** for **sickle cell** and **thalassaemia** disorders. These conditions are sometimes referred to as **haemoglobinopathies**. It is important that you consider early in your pregnancy whether you want to have these tests as they should be carried out as early as possible in pregnancy – ideally by 10 weeks.

### What are sickle cell and thalassaemia disorders?

Sickle cell and thalassaemia are inherited disorders that are passed on from parents to children through altered haemoglobin **genes**. These are serious, inherited blood disorders. They affect haemoglobin, a part of the blood that carries oxygen around the body. People who have these conditions will need specialist care throughout their lives.

People only have these disorders if they inherit two altered haemoglobin genes – one from their mother and one from their father. People who inherit just one altered gene are known as 'carriers'.

Carriers are healthy and do not have either sickle cell or thalassaemia. However, if a carrier has a baby with someone else who is also a carrier, or who has one of the disorders, there is a chance that their baby could have one of the disorders, or be a carrier too.

People who inherit two altered haemoglobin **genes** can go on to develop sickle cell disorder or thalassaemia.

#### Sickle cell disorder

People with certain types of sickle cell disorder:

- can experience attacks of very severe pain
- may have serious, life-threatening infections
- are usually anaemic (which means that their blood has difficulty carrying oxygen)
- will need medicines and injections when they are children, and throughout the rest of their lives, to stop them from getting infections.

#### Thalassaemia

People with certain types of thalassaemia:

- are very anaemic
- need blood transfusions every four to six weeks
- need injections and medicines throughout their lives.

There are also other, less common, haemoglobin disorders. Many of these are not as serious.

#### Screening for sickle cell and thalassaemia disorders

#### Who can be a carrier?

Anyone can be a healthy **carrier**. But you are more likely to carry the altered genes if your **ancestors** (parents, grandparents and those further back in your family line) came from places where malaria has been common. This is because being a carrier

This means you are more likely to carry the genes if your ancestors came from one of the countries in Africa; South Asia (for example, India, Pakistan or neighbouring countries); East and South East Asia countries (for example, mainland China, Hong Kong, Malaysia or their neighbours), the Caribbean, the Middle East, South America or the Mediterranean. People from Poland may also be affected because some Polish people migrated many generations ago from areas where malaria was common.

can help to protect people against malaria.

The professional taking care of you will ask you questions from a questionnaire (called the **Family Origin Questionnaire**) to help them find out whether you or your baby's father have a chance of carrying **genes** for these conditions. These questions aim to find out where your immediate family and your **ancestors** came from so we can assess whether you may have a higher chance of carrying these genes.

Please tell your **midwife** if you and your partner are related by blood, as this might be important. If you and your partner have both inherited genes from a shared relative, it may be more likely that both of you are **carriers** than if you were not related.

If you have an **assisted pregnancy**, this can affect the screening result. This is where pregnancy is assisted by controlling the way that the eggs and sperm are brought together. Sometimes this can involve using eggs or sperm which have been donated by someone else. The screening result can be affected if the donor is a possible carrier. Please give the staff as much information as you can so that we can give you the most accurate screening results possible.

#### Screening for sickle cell and thalassaemia disorders

#### What tests are involved?

You will be offered screening for **thalassaemia** using the Family Origin Questionnaire and the result of the blood sample. Depending on the results of this screening, further testing on the same blood sample for **sickle cell** may be carried out (we may request a further blood sample if the first is not clear but this is rare). If the result shows you are a carrier/have a haemoglobinopathy then partner testing will be offered and both results will then be used to see if your baby has a higher chance of having a **haemoglobinopathy**. If partner testing cannot be carried out for any reason the health professional will discuss your results and you may be offered a diagnostic test (see page 42).

Ideally the best time to have these tests is before you are 10 weeks pregnant, but it can still be helpful to have them later in pregnancy.

#### How the test can benefit you and your family

- If the test shows that you are a carrier, there is a chance other family members are too. You may want to encourage them to ask for a test, especially if they are planning to have a baby themselves.
- Although sickle cell carriers are healthy, they can experience some rare problems in situations when their bodies might not get enough oxygen (for example, when having an anaesthetic). Knowing that you are a carrier can help you manage these situations.
- People who are thalassaemia carriers do not experience these problems.

#### Are there any risks I should be aware of?

The **screening test** is a very simple blood test, with almost no risk to you or your baby.

#### How will I get my results?

The person taking the blood test will discuss this with you at the time.

#### What will the results tell me?

The most likely result is that you aren't a **carrier**. Your pregnancy should continue as normal. If the result shows that you are a carrier for **sickle cell** or **thalassaemia** disorders, the health professional taking care of you will talk to you about what this could mean for you, your baby and your family.

If we find that you are a carrier, we will invite your baby's father to have a test to find out if he is also a carrier.

In very rare cases, the test may show that one of you has a blood disorder without knowing it. If this happens, a health professional (for example, a nurse, doctor or **midwife**) will discuss this with you and give you more information.

The test is between 95% and 99% accurate, which means it is very reliable. However, in a very small number of cases the result may be unclear. If this happens, we will usually offer you another test.

#### Screening for sickle cell and thalassaemia disorders

### Why might my baby's father be invited for a test?

Babies can only inherit these disorders if both parents are carriers. So if you're a carrier, it is important to find out if your baby's father is also a carrier.

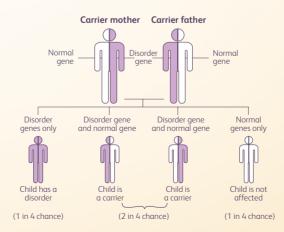
If he's not available or does not want to have the test, we may offer you another test to find out whether your baby has a sickle cell or thalassaemia disorder.

#### What if my baby's father is also a carrier?

If you and the baby's father both carry the **gene** for sickle cell, thalassaemia or another blood disorder, there is usually:

- a 25% (one-in-four) chance that your baby will not have a disorder
- a 50% (two-in-four) chance that your baby will be a healthy carrier
- a 25% (one-in-four) chance that your baby will have a disorder.

With each pregnancy, this chance stays the same.



#### Can my unborn baby be tested?

If you wish, you can choose to have a **diagnostic test** on your unborn baby (or **fetus**) when you are pregnant. This will show whether your baby has a disorder. We test your baby using either **chorionic villus sampling** or **amniocentesis**. See page 11 for an overview of these tests and page 42 for a fuller description. A health professional will explain the different types of test in detail and will help you to decide whether you want your baby to be tested. If you do want the test, it's important to have it as early as possible in your pregnancy.

Further information about diagnostic testing and referral to the fetal medicine team is provided on page 42.

If the results show that your baby has a blood disorder, the health professional taking care of you will help you to understand what this may mean for you, your baby and your family. They will talk with you about the care that is available and whether you wish to continue with your pregnancy.

#### Screening for sickle cell and thalassaemia disorders

#### Testing new babies for sickle cell disorder

As well as the tests described here, all newborn babies are offered a newborn 'blood spot' **screening test**, ideally when they are five days old. The test is done by taking some blood from your baby's heel. This test looks for a number of health problems, including **sickle cell disorders**. It will show whether your baby is unaffected, is a healthy **carrier**, or has a disorder. The blood spot screening test may occasionally detect some types of **thalassaemia**. We will give you more information about the tests for newborn babies later in your pregnancy (see **www.readysteadybaby.org.uk**).

#### Any questions?

If you have any questions about the tests, please discuss them with your **midwife** or **GP**. They will be able to give you advice and may also have information about other organisations which can offer support.

You may also find it helpful to talk to a **genetic counsellor** if the results of your tests leave you concerned about future pregnancies. A genetic counsellor is a professional who is specially trained to give you information and support if you are concerned about a condition which may be caused by a genetic abnormality, and who can help you to consider your options. Your midwife or GP will be able to refer you.

## Screening for infectious diseases



We will offer you a blood test for infections that can affect you and your baby, such as **hepatitis B**, **syphilis** and **HIV**. We screen for these conditions because simple treatments can reduce the risks to you and your baby.

There is a glossary at the end of this booklet. This explains the terms we usually use when providing pregnancy care, screening and diagnostic testing. Words in bold type are all in the glossary.

#### **Screening for infectious diseases**

#### Hepatitis B

Hepatitis B infection can be passed on from mother to baby during birth. Women infected with Hepatitis B may have no signs of infection but the virus can lead to serious liver disease. Without a test, you would not know if you're infected. If the test shows that you are infected with hepatitis B, we will provide specialist treatment.

A course of immunisation beginning at birth can usually prevent infection in babies born to infected mothers. Without immunisation, most babies born to mothers who are infected with hepatitis B will become infected themselves. These babies are at risk of developing serious liver disease as they grow older.

#### **Syphilis**

Syphilis is passed on through having sex. We test for it because if it is not treated it can damage the health of you and your baby. If syphilis is found, we can treat it quickly and simply with antibiotics.

More information about immunisations offered during pregnancy can be found at **www.immunisationscotland.org.uk** 

#### Human immunodeficiency virus (HIV)

**The human immunodeficiency virus (HIV)** is the virus that causes acquired immunodeficiency syndrome (AIDS). Infected women can pass HIV to their babies during pregnancy, childbirth and also through breastfeeding. Over time, HIV damages the immune system and destroys the body's defences against infection and disease.

It can take years for HIV to do enough damage for someone to become ill. Women with HIV will not know that they are infected unless they have a test.

If the test shows that you are HIV infected, specialists will offer you guidance and treatment. This will include medication that will greatly reduce the chance of you passing HIV infection to your baby. We will also give you advice about the best type of delivery and methods of feeding your baby. Medication to improve your own health can also be started if required.

If the **screening tests** for **syphilis** or HIV suggest that you might have either of these conditions, we will offer you a second test to confirm the results.

The organisations listed from page 47 can also provide information and support.

#### **Screening for infectious diseases**

#### Results of blood tests for infectious diseases

You will usually be able to get the results at your next clinic visit.

If we find any health problems, we will contact you as soon as possible and give you advice and care. We routinely repeat some tests later in pregnancy.

Occasionally technical problems can occur and we will ask you to have another sample taken.

Having a blood test does not affect current or future life insurance policies. However, if we find a health problem, this could affect your insurance. We would still recommend being tested. You might wish to check any policies you have for further details.

### What happens to my blood samples after testing is complete?

After they have been looked at, any of your leftover blood samples will be stored in the laboratory for at least 12 months. This is so that they can be used in the future if any test results need to be checked.

Your leftover blood samples may be used **anonymously** for other monitoring and laboratory purposes, such as comparing different screening methods and developing new tests. Sometimes leftover blood samples are also used anonymously for education and research to improve the quality of patient care.

Sometimes we may need to use samples that aren't **anonymous** – we will always ask for your consent before your samples are used in this way.

If you do not want your stored blood samples to be used for research, please ask the midwife to write 'no research' in the comments box on the request form.

# The screening test for Down's syndrome

A small number of babies are born each year with **Down's syndrome**. You may choose to have a test during pregnancy which can help to detect if your baby may have this condition.

#### What is Down's syndrome?

Most people have 23 pairs of **chromosomes**. These chromosomes carry the **genes** that determine how we develop. People with Down's syndrome (sometimes called 'trisomy 21') have an extra copy of chromosome 21 – they have three instead of two. This usually happens by chance and is not caused by anything parents do before or during pregnancy.

Older mothers are more likely to have a baby with Down's syndrome and the likelihood increases with a mother's age at pregnancy. For example, Down's syndrome occurs:

- once in every 1,500 births to women aged 20 years or younger
- once in every 900 births to women aged 30 years
- once in every 100 births to women aged 40 years.

However, Down's syndrome can occur in women of any age. It is sometimes inherited, but this is very rare.

All pregnant women, no matter what age, can have the test.

#### The screening test for Down's syndrome

There is no such thing as a typical person with Down's syndrome, but people with Down's syndrome do share distinctive physical characteristics.

Like all people, people with Down's syndrome vary a lot in appearance, personality and ability. People with Down's syndrome have learning disabilities. Some people with Down's syndrome have more serious difficulties than others. It is hard to tell in babies how much they will be affected as children, or when they are grown up. Some adults with Down's syndrome are able to get jobs and live fairly independent lives. However, most people with Down's syndrome need long-term help and support.

A number of health problems are linked to Down's syndrome, but people vary and some people with Down's syndrome enjoy good health. Problems which are linked to Down's syndrome include heart problems and reduced hearing and vision. Many of the problems can be treated and frequent health checks can make sure that any problems are picked up as early as possible. Most people with Down's syndrome live to be around 50 years of age, but some live to be over 70. Alzheimer's disease (a form of senile dementia) may affect people with Down's syndrome at an earlier age than other people.

#### Should I have the screening test?

Your **midwife** will discuss the test with you, and you should think about it very carefully. It is a personal decision for you to make and you should take time to think about it and to talk it through with the health professional taking care of you, as well as with your partner or people close to you. The final decision should be yours.

#### How is the test carried out?

There are two stages to testing for **Down's syndrome**.

The first stage is a **screening test**. We offer this to all pregnant women up to 20 weeks of pregnancy. You can choose whether to have this test or not.

We offer some women (about one in 50) a **diagnostic test**. These are mainly women who have a **'higher-chance' result** from the screening test. This usually means that there is a greater chance than one in 150 that their baby is affected. Again, you can choose whether or not to have this diagnostic test.

This will show whether your baby has a health problem. However, having this diagnostic test increases your chance of having a **miscarriage**. This is why it is not offered to all women. You can choose whether or not to have one or both parts of the testing process.

If the screening test shows the chance of the baby having Down's syndrome is low, we will not offer you a diagnostic test. Most screening test results (more than 95%) fall into this category. This is known as having a **'lower-chance' result**.

It's important to understand that a lower-chance result does not mean that there is no chance at all that your baby has Down's syndrome, just that it is unlikely. There is still a small possibility, because some babies with Down's syndrome aren't detected by screening tests. Overall, about 10% of babies (one in ten) with Down's syndrome will not be detected by screening.

#### The screening test for Down's syndrome

### What type of screening test for Down's syndrome will I be offered?

There are different ways of screening for Down's syndrome. We will either offer you a blood test combined with a special **ultrasound scan** (if you are less than 14 weeks pregnant) or a blood test on its own (if you are between 14 and 20 weeks pregnant). Sometimes we will find that you are at a different stage of pregnancy than you had thought originally, and we will need to change the type of tests that we offer you as a result. This is usually identified at your early pregnancy scan.

#### **Blood tests**

The blood test measures substances that have passed between you and your baby. A sample of your blood is usually taken between 11 and 20 weeks.

Several factors can affect the screening result, including if you smoke or if you have an **assisted pregnancy** (especially if it involves a **donor egg** or **frozen embryo**). It is important that you give the staff this information in order for you to be given the most accurate screening result possible.

A computer programme then uses the results of your blood test, along with your age, weight, stage of pregnancy and any other relevant factors, to work out the chance of the baby having Down's syndrome.

#### Nuchal translucency ultrasound scan

Further information about how to prepare for the **ultrasound scan**, and how it is performed, is provided on page 38.

A **nuchal translucency (NT) scan** is an ultrasound scan carried out between 11 and 14 weeks of pregnancy, usually as part of your early pregnancy scan. We measure the amount of fluid lying under the skin at the back of the baby's neck. A computer programme uses this measurement, along with your blood test result, to work out the risk of your baby having **Down's syndrome**. This is sometimes known as the **'combined' test**.

If you are having twins or triplets, we can use the ultrasound test on its own to work out the chance of each individual baby having Down's syndrome.

### Can any other types of abnormality be detected by screening?

Occasionally, **screening tests** may detect some other abnormalities. Some of these can be serious, while others will have only a small effect on the baby or won't affect them at all. If the tests show that there may be a problem, we will give you information on the options available and support to help you make your decisions.

#### The screening test for Down's syndrome

# What if the screening test shows a higher-chance result?

If the screening test shows a 'higher-chance' result, we will offer you a follow-up diagnostic test to confirm whether your baby has Down's syndrome. The health professional will talk this through with you and answer any questions you have. We will fully explain these follow-up diagnostic tests to you and you will have the option to accept or refuse them.

# What are the diagnostic tests offered for Down's syndrome?

The second stage of testing for Down's syndrome involves either **chorionic villus sampling (CVS)** or **amniocentesis.** These are two approaches to diagnostic testing for Down's syndrome and will be offered to you if you have a 'higher-chance' result. See page 11 for an overview of these tests and page 42 for a fuller description. If you are offered one of these tests you should read these sections carefully before deciding whether to accept the test.

Further information about diagnostic testing and referral to the **fetal medicine team** is provided on page 45.

# Scans

# Early pregnancy scan

We perform the first scan to estimate the stage of pregnancy, to assess growth and development, and to check your baby's heartbeat. This scan is sometimes referred to as a 'booking' or 'dating' scan. Very occasionally we can see some other abnormalities in your baby during this scan. If you do not want to know about these, please discuss this with your midwife.

If you book early enough in pregnancy we will also offer to perform a nuchal translucency measurement to help assess the risk that your baby has **Down's syndrome**. This is sometimes called a **nuchal translucency (NT) scan**, and we offer this between 11 and 14 weeks of pregnancy. This is part of the screening test for Down's syndrome described on page 32.

If you would like an early pregnancy scan but do not want to know your baby's risk of having Down's syndrome or other conditions, please discuss this with your midwife.

# Mid-pregnancy scan

This scan, sometimes called a fetal anomaly scan, is performed between 18 and 21 weeks of pregnancy.

Further information about how to prepare for the **ultrasound scan**, and how it is performed, is provided on page 38.

**Scans** 

# What can a mid-pregnancy scan tell me about my baby?

During the scan, the health professional will take a very careful look at your baby.

Most people find that their baby is healthy and developing well. Sometimes, however, we find a problem. In most cases the problems we see are minor and the health professional taking care of you will be able to explain them to you. More rarely, we detect serious problems.

# Can the mid-pregnancy scan detect all problems?

No. Sometimes the **sonographer** is not able to get a clear view because of your baby's position or age, the amount of amniotic fluid surrounding your baby, your own bodyweight, or any scar tissue left by an abdominal operation, such as a previous **Caesarean section**. Also, some health problems only develop after 18 to 21 weeks (when we offer you a scan) and there are some problems we can never see on a scan because they have no effect on the appearance of the baby. This means that in a small number of cases, babies are born with health problems that we were not able to pick up through the scan.

# What kind of problems can be seen on the mid-pregnancy scan?

We can diagnose some but not all major health problems affecting the development of the baby, for example, in the brain, spinal cord, heart, bowel, kidneys and limbs. Although, in these cases, the sonographer and doctors can usually be confident in the findings, no **screening test** will detect all cases.

other problems, such as some heart defects.

Sometimes we pick up minor irregular features of the baby's body. Usually these mean nothing at all, but sometimes we can see a pattern which might suggest an underlying problem.

Scans are not as reliable at detecting some

Please ask your **midwife** if you would like to know full details of the scan's findings.



**Scans** 

# What will happen if a problem is found or suspected?

If we find or suspect a problem, the **sonographer** may ask for a second opinion from another sonographer or doctor. We will tell you what the concerns are, but the exact nature or extent of the problem might not be clear at this stage.

### Will I need another scan?

If the baby appears to be healthy on the mid-pregnancy scan, you probably won't need another scan during this pregnancy, unless your midwife or **obstetrician** think that it is necessary – for example, if you take some types of medication or have a long-term medical condition. If the sonographer is not able to see everything clearly, we may need to repeat the scan on a different day. This happens quite often.

# Can anything be done before the birth?

Finding out about a health problem before birth can help parents to prepare themselves. Sometimes it can help them to plan treatment after the baby is born. For example, if your baby has a problem that will need an operation soon after birth (such as repairing a hernia in its tummy) we can arrange for you to deliver your baby in a hospital where this can be done within the first few hours after birth.

# Can the baby have an operation before birth?

For some conditions this is possible, but unfortunately, very few problems can be treated in this way.

# Having a scan

# Ultrasound scanning

The early pregnancy scan and mid-pregnancy scan are described on page 10, with some further detail on **nuchal translucency** measurement on page 32.

In addition, we will offer you further scans if there are specific indications to do so – for example, to monitor the growth of your baby or to check the position of the **placenta**.

#### What kind of scan will I be offered?

Most scans are carried out by trained health professionals called **sonographers**.

We will offer you scans that produce a two-dimensional black and white image. The three-dimensional (3D) and colour scan images you sometimes see on television and in magazines are not routinely used in the NHS screening programme.

# How accurate are scans?

Scans have their limitations. Your health professional may tell you that there might be a problem, but will not be able to say for certain. In a small number of cases, babies are born with health problems that were not picked up by the scan.

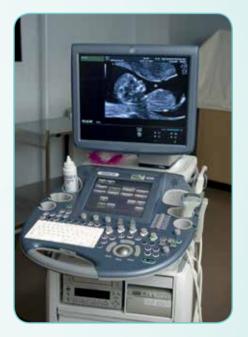
#### Having a scan

### Are scans safe?

**Ultrasound scans** are considered completely safe for mother and baby.

# How can I prepare for the scan?

You will be asked to drink some water before attending for the scan so that you have some fluid in your bladder. This helps the sonographer record better pictures of your baby. The amount of water that you will be asked to drink will depend on the stage of pregnancy. You should have a full bladder for the early pregnancy scan, so should drink about a pint (around 500ml) an hour before the scan. Your bladder does not need to be full before the midpregnancy scan, but drinking a glass or two of water will help the sonographer.



Ultrasound machine used by sonographers during a scan

# Can I bring family or friends with me when I have the scan?

Hospitals have different policies about this, and it is a good idea to check beforehand. Most hospitals welcome partners in the room. Please let us know ahead of time if you need an **interpreter** so that we can arrange one for you. You can usually take both your partner and the interpreter into the room with you. Young children may not be allowed because they can distract the **sonographer**.

# What will happen when I go into the scan room?

In order for the sonographer to take good quality images of your baby, the room will be dimly lit. Scanning requires a lot of concentration, especially if your baby is very active. The sonographer will ask you to lie on a couch, raise your top up to your chest and lower your skirt or trousers to your hips. They will apply **ultrasound** gel to your abdomen and tuck paper around you to protect your clothing.

The sonographer then passes a hand-held device across your abdomen, which sends and picks up ultrasound waves. These waves allow the computer to build an image of your baby. The scan does not hurt at all, but the gel might be a little cold at first. Occasionally the sonographer may need to apply slight pressure to your abdomen if some parts of your baby are difficult to see (see scan machine on page 39).

# How long will my scan take?

A scan can take anything from 10 to 40 minutes. The images created on the screen are usually recognisable, for example you may see your baby's head, heart and limbs. However, the sonographer may not be able to get clear pictures, depending on the position of your baby and whether your baby is moving around a lot.

If you are overweight, this can reduce the quality of the scan image. If it is difficult to get a good image, scanning may take longer, or we may have to repeat it at another time.

The vast majority of scans show that the baby is healthy and no problems are found. This is because most babies are healthy.

# Will the sonographer tell me the sex of my baby?

It is not the purpose of the scan to look for the sex of the baby unless there is a medical reason for doing so. Often it is impossible to tell because of the position of the baby, it is not completely reliable and can turn out to be wrong.

# Can I have a picture of my baby?

You will need to check if your hospital provides this service. If they do, there may be a charge.

# Diagnostic testing and follow-up

# Diagnostic testing: chorionic villus sampling and amniocentesis

This section describes the **diagnostic tests** that may be offered to you during pregnancy and the ways that follow-up may be arranged. You should read this alongside the specific information about individual **screening tests** in earlier sections.

These tests are offered to women who have a 'higher-chance' result from screening for sickle cell disorder, thalassaemia or **Down's syndrome**, and in some other circumstances.

# Chorionic villus sampling (CVS) and amniocentesis

**CVS** can be done from 11 weeks of pregnancy. It is usually only offered in a specialist centre. With the help of an **ultrasound scan**, an **obstetrician** will guide a fine needle through your abdomen, or much more rarely through your cervix, and will take a small sample of tissue from the **placenta**. We analyse this in the laboratory and count the baby's **chromosomes**. For around two in every 100 samples, CVS does not produce a clear result. If this happens, we may offer you further tests.

#### Diagnostic testing and follow up

Amniocentesis can be carried out after 15 weeks of pregnancy. It usually takes about 10 minutes. We will perform an ultrasound scan to check the position of your baby in the womb. An obstetrician will then insert a fine needle through your abdomen, into your womb. We use the needle to take a sample of fluid surrounding the baby (called 'amniotic fluid'). This fluid contains cells from the baby which will be examined later at the laboratory. The baby's chromosomes will be counted as well. For around one in every 100 samples the results are not clear. If this happens, we may offer you further tests.

# Are these tests painful?

While many women find the procedures uncomfortable, they shouldn't be painful. For a day or two afterwards, you should take things easy and avoid strenuous exercise. You may have some discomfort in your lower abdomen for a day or two after the procedure. This is normal, and you can take paracetamol to relieve the discomfort. If symptoms persist, please contact your **midwife**.

# How safe are these diagnostic tests?

They are not completely safe, and this is why we don't offer them to everybody.

For every 100 women who have CVS, one or two will have a **miscarriage**. For every 100 women who have amniocentesis, one will miscarry. If you would like to know more about the miscarriage rates after CVS or amniocentesis in your hospital, please ask the health professional taking care of you.

# What happens if the diagnostic test finds a problem?

In most cases, follow-up testing finds a healthy baby. If the testing finds a **chromosome** variation, the health professional will talk to you about it and the options that you have. Then you'll be able to choose what you feel is best for you. Some people may decide to continue with the pregnancy, while others will feel that **termination of pregnancy** is right for them. Termination is when a pregnancy is ended, either by taking medicines or by surgery.

There will be no pressure to influence you in your decision – the hospital staff will provide you with help and support whatever you decide.

The organisations listed at the back of this booklet can also provide further information and support.

#### Diagnostic testing and follow up

### Referral to the fetal medicine team

If we offer you further tests, the health professional taking care of you will give you more information and may refer you to the **fetal medicine team**. This is a team that includes a specialist doctor, **midwife** and other health professionals. Members of this team may offer you further tests and will provide further information and advice about any health problems you or your baby might have. This could be in another hospital. We will usually give you an appointment within a few days.

In most cases, further tests don't find any health problems.

However, they can cause great worry for parents and for some people this worry can continue throughout the rest of their pregnancy. You may want to ask questions and talk about these concerns with your own midwife, doctor or consultant. Other sources of information and support are listed at the back of this booklet.



# If a definite health problem is found, what happens next?

What happens next will depend on what the condition is and how serious it is. Some problems may turn out not to be serious and others will get better on their own. We may offer you further scans throughout the pregnancy to monitor these problems.

If the health problem is serious, the health professional caring for you will discuss your options with you, which may include having a **termination** or preparing for the birth of a seriously ill baby. If you need to make any decisions, your **midwife** and the hospital team will give you time, support and information.

Contact details of organisations and support groups that you might find helpful are given in the next section.

More information and further help

# More information and further help

Thank you for taking the time to read this booklet. The information can be a lot to take in. Please talk to the health professional taking care of you if you have any questions or concerns.

We have listed contacts you may also find useful for advice and support. Some of these organisations are able to work in minority languages or provide **interpreters**, but for others this may be more difficult.

#### **NHS** inform

Tel: 0800 22 44 88

Textphone: 18001 0800 22 44 88 (the helpline is open every day 8 am to 10 pm and also provides an interpreting service)

www.nhsinform.co.uk/screening/pregnancy

# Antenatal results and choices (ARC)

Provides non-directive support and information to expectant and bereaved parents throughout and after the pregnancy screening and **diagnostic testing** process.

Tel: 0845 077 2290 or 0207 713 7486 from a mobile phone (Calls cost 0p per minute plus your phone company's access charge.)

www.arc-uk.org

# **Contact a Family Scotland**

Provides information, advice and support to parents and carers of children with any special need or disability.

Tel: 0808 808 3555 (free) (voice and text) www.cafamily.org.uk

Contact a Family can advise people who contact them through a telephone **interpreter**. Some of their publications are available in different languages on their website through the following link: www.cafamily.org.uk/advice-and-support/resource-library/

# Down's Syndrome Scotland

Works to help people with **Down's syndrome** reach their full potential by providing information and support to them, their families, carers and professionals.

Tel: 0131 313 4225 www.dsscotland.org.uk

# **Positively UK**

Offers a range of peer support, advice, information and advocacy services for **HIV** positive women and men.

Tel: 020 7713 0444 www.positivelyuk.org

#### More information and further help

# Scottish Spina Bifida Association

Offers a multi-faceted family support service to those affected by spina bifida, hydrocephalus and allied conditions, across Scotland.

Helpline: 03455 211 300 (calls charged at local rate)

General enquiries: 03455 211 811 (calls charged at local rate)

www.ssba.org.uk

The Scottish Spina Bifida Association can provide support through an interpreter.

# **Sickle Cell Society**

Offers information, counselling and care for people with **sickle cell** disorders and their families.

Tel: 020 8961 7795

www.sicklecellsociety.org

#### **SOFT UK**

Supports families affected by Patau's Syndrome (Trisomy 13), Edward's syndrome (Trisomy 18), partial Trisomy, mosaicism, rings, translocation, deletion, and related disorders.

www.soft.org.uk

# **UK Thalassaemia Society**

Provides education and information to those affected by thalassaemia. They publish information about thalassaemia in different languages.

Tel: 020 8882 0011

www.ukts.org

# **Waverley Care**

Provides care and support to people living with **HIV** and hepatitis C and their partners, families and carers.

Tel: 0131 558 1425 www.waverleycare.org

#### Healthtalkonline

This website provides short recorded interviews and written descriptions of people's experiences of health procedures, tests and conditions. This includes experiences of pregnancy screening and diagnostic testing, including those for sickle cell and thalassaemia disorders and termination of pregnancy following diagnosis of a fetal abnormality. Some of the recordings about people's experiences are in different languages, including Urdu, Sylheti, Mirpuri, French and Portuguese.

www.healthtalkonline.org

# **British Pregnancy Advisory Service**

BPAS provides help to women with an unplanned pregnancy or a pregnancy they choose not to continue with.

Email: info@bpas.org

Tel: 03457 30 40 30 (calls charged at local rate)

www.bpas.org/bpaswoman

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# Glossary

#### **Amniocentesis**

This is a test that can be done after 15 weeks of pregnancy, usually to diagnose whether your baby has **Down's syndrome**. A tiny amount of the fluid surrounding your baby (called 'amniotic fluid') is collected by a needle through the mother's abdomen. We use an **ultrasound scan** to guide this. The fluid contains cells which are grown in the laboratory to check your baby's **chromosomes**. This is an invasive test that carries a small risk of **miscarriage**.

#### **Ancestors**

Parents, grandparents and those further back in your family line.

### **Anonymously**

If your leftover blood samples are used anonymously (for example, in research), this means that your name is not given on the samples and the person using the samples would not be able to find out that they had come from you. If a leftover blood sample needed to be used with your name given, you would always be asked to give your **consent**.

#### **Antenatal**

Occurring before birth, during pregnancy.

### **Anti-D** injections

The anti-D injection is offered to **Rhesus negative** women. This is because there is a slight risk that if their baby is **Rhesus positive**, and their blood mixes during pregnancy, antibodies may form that can cause complications in future pregnancies. An antibody is a protein produced by the body's immune system when it detects apparently harmful substances. In future pregnancies, if the baby is Rhesus positive, these antibodies may attack and destroy the baby's red blood cells, causing anaemia, jaundice, or liver or heart problems. These problems can be prevented by giving Rhesus negative mothers an injection of anti-D.

### Assisted pregnancy

Where pregnancy is assisted by controlling the way that eggs and sperm are brought together. Sometimes this can involve using eggs or sperm which have been donated by someone else. Results of **screening tests** can be affected if the donor is a possible **carrier**.

#### Caesarian section

A surgical cut into the womb in order to deliver a baby.

#### Carrier

In this leaflet, 'carrier' refers to a person who carries one faulty copy of a **gene** for a particular condition (for example, **sickle cell** disorder or **thalassaemia**) but who is generally not affected with the condition and is usually healthy.

### Chorionic villus sampling (CVS)

A test that is done from 11 weeks of pregnancy where a small number of cells are taken from the **placenta** and sent to the laboratory for testing. This sample is collected by a needle through the mother's abdomen, or more rarely through her cervix. We use an **ultrasound scan** to guide this. This is an invasive test that carries a small risk of **miscarriage**.

#### **Chromosomes**

These are structures which contain **genes.** Humans usually have 46 chromosomes, 23 inherited from our mother and 23 from our father.

#### 'Combined' test

A test using a computer programme to combine results from the **nuchal translucency** scan with your blood test result, your age and some other information to work out the chance of your baby having **Down's syndrome**.

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# Confidentiality

Any information you give to a health professional, or information held about you in the NHS, cannot be shared with anyone except authorised NHS staff unless you give your permission. NHS staff must keep your information confidential by law.

#### Consent

Agreeing to a test, investigation or treatment. Before a doctor, nurse or any other health professional can examine or treat you, they must have your consent. In order to consent, you must be given enough information, and you should be allowed to make up your own mind without pressure from other people. We will usually ask you to sign a form giving consent to tests, treatment or investigations.

#### Diagnostic test

A test which is carried out following a **screening test** result to find out whether your baby actually has a particular condition. We usually offer a diagnostic test if the result of a screening test shows that your baby has a higher than normal chance of having the condition. Some diagnostic testing is carried out through **amniocentesis** or **chorionic villus sampling (CVS)**. These tests are invasive and carry a small risk of miscarriage.

#### **Donor egg**

An egg provided by another woman that is then fertilised in the laboratory.

#### Down's syndrome

People with Down's syndrome have learning disabilities. Some people have more serious difficulties than others, and other health problems are sometimes associated with Down's syndrome. Most people with Down's syndrome need long-term help and support, although some people can lead independent lives. People with Down's syndrome have three instead of two copies of **chromosome** 21, and the condition is sometimes called 'tristomy 21'. This usually happens by chance and is not caused by anything parents do before or during pregnancy.

#### False-negative result

**Screening tests** divide people into lower and higher chance groups. Some people with a lower-chance screening test result do actually have the condition being screened for. These people are said to have a 'false-negative' result.

### False-positive result

**Screening tests** divide people into lower and higher chance groups. Some people with a higher-chance screening test result do not actually have the condition being screened for. These people are said to have a 'false-positive' result.

### Family Origin Questionnaire

This is a sequence of questions that the health professional leading your care will ask you to find out which part of the world your immediate family and your **ancestors** came from. This is so that they can find out whether you might have a higher than normal chance of carrying **genes** for conditions which are common in certain areas.

#### Fetal medicine team

This is the term used in some areas for specialist midwives and doctors who provide support to women with a 'higher-chance' result.

#### **Fetus**

The unborn baby developing in the womb/uterus.

### Frozen embryo

A fertilised human egg cell that is held in frozen storage.

#### Gene

The basic unit that transfers genetic characters from parents to babies. Genes make up the structure of **chromosomes**.

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#### **Genetic counsellor**

A professional who is specially trained to give you information and support if you are concerned about a condition which may be caused by a genetic abnormality, and who can help you to consider your options.

#### **GP** (General Practitioner)

Family doctor.

### Haemoglobinopathies

Disorders of the part of the red blood cells which carry oxygen around the body. These disorders are usually inherited from parents through **genes**. **Sickle cell disorders** and **thalassaemia** are two of the most common forms of haemoglobinopathy.

### Hepatitis B

A virus that affects the liver and can be carried for many years in the blood before causing signs of illness. Hepatitis B infection can be passed on from mother to baby during birth, but immunisation at birth can usually prevent infection in babies born to infected mothers. Without immunisation, many babies born to mothers who are hepatitis B carriers become infected and are at risk of developing serious liver disease as they grow older.

# 'Higher-chance' result

Where the result of a **screening test** suggests that your baby has a higher chance of having a particular condition. If you have a 'higher-chance' result you will usually be offered a **diagnostic test** to see if your baby actually has that condition.

#### Human immunodeficiency virus (HIV)

The virus that causes acquired immunodeficiency syndrome (AIDS). Infected women can pass HIV to their babies during pregnancy, childbirth and also through breastfeeding. HIV damages the immune system and destroys the body's defences against infection and disease. Specialist help is available and medication and advice on the best kind of delivery and methods of feeding your baby can greatly reduce the chance of the infection passing to your baby. Medication can also be given to improve your health if required.

#### Interpreter

A person who translates between two people who do not speak the same language.

#### 'Lower-chance' result

Where the result of a **screening test** suggests that your baby has a lower chance of carrying a particular condition. This usually means that you will not need to have a **diagnostic test** for this condition. A 'lower-chance' result does not mean that there is no chance at all that your baby has that condition, just that the chance is low.

#### Midwife

Midwives are highly skilled, qualified professionals who provide expert clinical care for women during normal pregnancy, childbirth and after birth. They are trained to make sure everything goes as well as possible and to recognise any potential problems for you and your baby. Midwives work in hospitals and in the community as part of a team. Other members of that team may also care for you during your pregnancy or after the birth of your baby.

### Miscarriage

An unplanned end to pregnancy before 24 weeks when the fetus moves outside the womb and is unable to survive on its own.

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### Nuchal translucency (NT) scan

An **ultrasound scan** done between 11 and 14 weeks of pregnancy, which is usually part of your early pregnancy scan that measures the pocket of fluid at the back of the baby's neck. An increased amount of fluid may mean the baby has an increased chance of having **Down's syndrome**. A computer programme uses this measurement, along with your blood test result, your age and some other information to work out the chance of your baby having Down's syndrome. This is sometimes known as the **'combined' test**.

#### Obstetrician

Obstetricians are doctors who specialise in pregnancy and childbirth. In Scotland they usually only see women who have complications during their pregnancies, or who need extra care.

#### Placenta

This is on the inside of the mother's womb and links the mother's blood supply with her unborn baby. The baby gets nourishment from the placenta.

### Rhesus positive and Rhesus negative.

Women who are Rhesus positive have a substance called the Rhesus antigen on their red blood cells. Those who are Rhesus negative do not have this antigen. About one in six women are Rhesus negative. Problems can occur when a Rhesus negative mother is carrying a Rhesus positive baby if the baby's blood enters her blood stream. This is not a problem during a first pregnancy, but can cause serious problems in future pregnancies. 'Anti-D' injections are offered to Rhesus negative women to avoid these problems.

#### Screening test

This test estimates your chance of having a baby with a certain condition. It cannot tell you for certain whether your baby has a particular condition. Screening tests in pregnancy are usually scans or blood tests which won't affect your baby's development in any way. If the screening test shows that you have a higher than normal chance of having a baby with a particular condition, you will usually be offered a **diagnostic test.** 

#### Sickle cell disorder

A serious blood disorder passed on from parents to children through altered haemoglobin **genes**. People can develop this when they inherit two altered haemoglobin genes (one from their mother and one from their father). People who inherit one altered gene are normally healthy and are called **carriers**. People with certain types of sickle cell disorder can experience attacks of severe pain, infections and anaemia (which means that their blood has difficulty carrying oxygen) and will need specialist care throughout their lives.

# Sonographer

Sonographers are the professionals who carry out **ultrasound scans** to check for abnormalities and to measure your baby's growth and due date.

### **Syphilis**

An uncommon infection, passed on through having sex, which can be treated quickly and simply with antibiotics. If it is not treated it can damage the health of you and your baby.

# **Termination of pregnancy**

Sometimes also called an abortion, this is ending a pregnancy by taking certain medicines or having surgery. In Great Britain (England, Scotland and Wales) termination can be carried out legally up to 24 weeks of pregnancy, but it can also be carried out after that if a woman's life is at risk, or if her baby will be born with a severe disability.

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#### Thalassaemia

A serious blood disorder passed on from parents to children through altered haemoglobin **genes**. People can develop this when they inherit two altered haemoglobin genes (one from their mother and one from their father). People who inherit one altered gene are normally healthy and are called **carriers**. People with certain types of thalassaemia are very anaemic (which means that their blood has difficulty carrying oxygen) and need blood transfusions and other medical care throughout their lives.

#### **Trimester**

The nine months of pregnancy are divided into three month periods called trimesters. The first three months are the first trimester, the second three months are the second trimester and the third three months are the third or final trimester.

#### Ultrasound scan

A painless test that uses sound waves to create images of the growing baby during pregnancy. It is usually carried out by passing the head of the scanner across the skin of the abdomen (tummy). This publication is available online at **www.healthscotland.com** or telephone **0131 314 5300**.

#### **Traditional Chinese**

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#### Urdu

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This resource is available in Urdu, Chinese and Polish, and in an Easy Read format. NHS Health Scotland is happy to consider requests for other languages and formats.

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