Testing for Down’s syndrome in pregnancy

An easy-read book
This book was produced by The Elfrida Society for the NHS Fetal Anomaly Screening Programme.

Screening Programmes

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You might not want to read all of this book. It will depend on the results of your tests. Only read each part if you want to and if you feel that it matters to you.
Testing for Down’s syndrome in pregnancy

All pregnant women are now offered tests to see if their baby might have Down’s syndrome.
The tests can only be offered before you are 20 weeks pregnant. This is about 5 months.
This book tells you about Down’s syndrome.
It also tells you about the tests.
This book will help you to decide whether to have the tests or not.

Choosing whether to have the tests is a big decision.
You will want to make a choice that feels right for you and your baby.
Read this book carefully and talk to people you trust about your decision.
This could be your family, your partner, friends or people who work with you.
It could also be your midwife or doctor. They will talk to you about Down’s syndrome.
Anyone can have a baby with Down’s syndrome.
Some people think that having the test will help you to get ready.
Other people wait until the baby is born.

There are lots of helpful people and organisations that you can talk to.
There is a list at the back of this book.

It is important that you tell someone if someone else is trying to tell you what to decide.
Talk to your advocate about this.
This is your decision.
Advocacy

An advocate is someone who can support you to speak up for what you want.
It is someone you can trust.

Advocates can support you with difficult decisions.
They do this by supporting you to look at information and think about what you want.
They can support you to talk to other people about what you want.

How do I find an advocate?

If you have staff working with you, tell them you would like an advocate.
If you live independently you can call the Duty Social Worker at your local Learning Difficulties Team.
They are part of the council.
The number will be in the phone book.
You can also call the Advocacy Finder Helpline on 08451 22 86 33
They are open from 2 – 5pm.

Action for Advocacy also has a website that can help you find an advocate.
The address is:
www.actionforadvocacy.org.uk
What is it like to have Down’s syndrome?

Everybody is different.

People with Down’s syndrome have different abilities and personalities just like everybody else.

You might know someone with Down’s syndrome.

People with Down’s syndrome have learning difficulties.

This means that they might need extra support as they grow up.

Anyone can have a baby with Down’s syndrome.
Babies with Down’s syndrome can be as healthy as any other child. They can also have a few health problems. Just like any other child. About half of them have a heart or bowel problem. This will need an operation. Your baby might have the operation after it is born. Or wait until they are older and stronger.

This picture shows you where the heart and bowel are in your body.
How do the tests work?

There are two tests that you can choose to have.

The first test is called a screening test.

The second test is called a diagnostic test.

The screening test

The screening test is offered to everyone.

It does not give a definite answer.

Everyone has a chance of having a baby with Down’s syndrome.

The test tells you how big your chance is of having a baby with Down’s syndrome.

You will be told what the chance is in numbers.

You might hear people talk about a 1 in 100 chance or a 1 in 1500 chance.

People sometimes say risk instead of chance. They mean the same thing.
1. **Screening tests**

- Blood test or Ultrasound

2. **Results**

- low chance
- high chance

- no more tests

3. **Diagnostic tests**

- Amniocentesis or CVS
1 in 100 is a small chance.

1 in 100 means that for every 100 pregnant women, 1 woman will have a baby with Down’s syndrome.

1 in 1500 is a very small chance.

1 in 1500 means that for every 1500 pregnant women, 1 woman will have a baby with Down’s syndrome.

As the second number gets bigger, the chance gets smaller.

If the screening test shows that you are more likely to have a baby with Down’s syndrome you will be offered a diagnostic test.

The diagnostic test can be harmful for your baby.

A small number of babies die because of the diagnostic test.

This is called a miscarriage.

It is a small chance. About 1 in 100.
A 1 in 100 chance means that for every 100 pregnant women, 1 woman will have a baby with Down’s syndrome and 99 will have a baby without Down’s syndrome.
What are the screening tests?

There are different ways of doing the screening test.
Different hospitals use different tests.
The two most common tests are a blood test and an ultrasound scan.

The blood test

A blood test looks at a sample of blood from the mother.
It can be done when the mother is between 10 and 20 weeks pregnant.
This means between 2½ and 5 months.
You will be asked how old you are and how much you weigh.
The information is put into a computer.
The computer uses this information to work out the chance of your baby having Down’s syndrome.
A blood test looks at a sample of blood from the mother
The ultrasound scan

The ultrasound will show a picture of your womb on a screen like a TV.
The womb is where the baby grows.
You will have some gel put on your tummy.
The person doing the scan will roll a thing that looks like this over your tummy.
You will be able to see your baby on the screen.
The scan is done when you are 11 to 14 weeks pregnant.
It measures the fluid under the skin at the back of the baby’s neck.
A computer uses this measurement and compares it to the size of the baby and your age.
It can then work out the chance of your baby having Down’s syndrome.
Some hospitals use both the blood test and the ultrasound scan.
Ask what tests you will be offered.
What happens next?

Ask your doctor or midwife how you will get the results of the test.
Tell your doctor or midwife how you would like to know.
It can take up to two weeks to get the results.

Women who are not offered more tests

Most people find out that there is only a small chance of having a baby with Down’s syndrome.
They are not offered any more tests.
Their baby might still have Down’s syndrome.
But the chance is very small.
Women who are offered more tests

Some women are offered a second test.

This is called the **diagnostic** test.

You will be offered the diagnostic test if the doctor thinks there is a higher chance your baby has Down’s syndrome.

It does not mean that your baby definitely has Down’s syndrome.

Most women who have the diagnostic test find out that their baby does not have Down’s syndrome.
What if I am offered more tests?

If you are offered more tests your doctor or midwife will give you information and support.

You can ask to have this information in easy read format.

The tests you will be offered are the diagnostic tests.

You have to decide whether you want to have more tests.

You can decide not to have more tests but you might worry about your baby.

Or you can decide to have the tests.

But these tests can be dangerous and a small number of babies don’t live after having the tests.

This is a big decision and you might want support.

You can talk to an advocate about your decision. It is important to remember that it is your decision.

It is important that you tell someone if someone else is trying to tell you what to decide.

Find out if there is an advocacy service in your area and ask for support.
You can talk to an advocate about your decision. It is important to remember that it is your decision.
What are the diagnostic tests?

There are two types of diagnostic test.

One is called chorionic villus sampling or CVS.

CVS can be done from 11 to 13 weeks of pregnancy. This is nearly 3 months.

The other is called amniocentesis.

Amniocentesis can be done from 16 to 18 weeks of pregnancy. This is 4 months.
Chorionic villus sampling (CVS)

CVS can be done from 11 weeks of pregnancy. This is nearly 3 months.
It is usually only done in special centres.
An ultrasound scan is used to see where the needle should go into your womb.
The needle either goes through your vagina or through your tummy.
A small sample is then taken from the placenta.
The picture on the next page shows the placenta.
Sometimes the test doesn’t work and you’ll be offered another one.
This picture shows the placenta in the womb.

The placenta grows in the womb with the baby and gives the baby food and air.

The placenta is coloured in red next to the baby.
Amniocentesis

First you will have an ultrasound scan.
This tells the doctors where the baby is in your womb.
A thin needle will then go through your tummy into your womb.
The needle will not touch your baby.
The needle will take a small amount of fluid from around the baby.
This is called amniotic fluid.
The fluid contains cells from the baby.
These can be looked at in a laboratory.
Sometimes it doesn’t work properly and you will be offered another test.
A thin needle will go through your tummy into your womb. The needle will take some fluid from around the baby.
Are the tests safe?
The tests are not completely safe.
A small number of people lose their baby after having the tests.
This is called a miscarriage.

Are the tests painful?
Many women find the tests uncomfortable but they should not be painful.
You should rest for a day or two after having the tests.
Avoid lifting, bending or stretching.
You may feel a mild pain in your tummy afterwards.
You might be able to take paracetamol for this.
Talk to your doctor or midwife about it first.
You should only take painkillers when pregnant if your doctor tells you it’s okay.
You may want to rest for a day or two after having the tests. Avoid lifting, bending or stretching.
How long does it take to get the results?

It can take up to 18 days to get the results of your diagnostic test.
Some hospitals offer newer tests that give some information after 2 – 3 days.
But you will still have to wait up to 18 days for the results of the diagnostic tests.

How will I get the results?

Talk to your midwife.
Tell them how you would like to be told about the results.
Some people prefer to be told in person.
Others like to find out by phone or by letter.
Talk to your midwife about what is best for you.
What will the tests tell me?

There are 3 possible results from the tests.

- Your baby does not have Down’s syndrome.
- Your baby does not have Down’s syndrome but there is another problem.
- Your baby has Down’s syndrome.
If you are told your baby does not have Down’s syndrome

This is the result that most women get.

Some women don’t want to talk about the tests any more.

Other women want to talk about the tests with somebody.

This could be because they are confused about why the two tests said different things.

The next page tells you why the tests might say different things.

If you don’t want to know anymore just put the book down.

Remember that the diagnostic test gives the definite answer.
Why did the tests say different things?

The screening test looks for things that might show that your baby has Down’s syndrome.

There are other reasons for those things showing up on the tests.

Only the diagnostic test can tell what those things are and if your baby has Down’s syndrome.

Talk to someone if you are confused or upset about this.

You can talk to your midwife or doctor.

Ask your advocate to support you if you have one.
Your baby does not have Down’s syndrome but there are other problems.

Sometimes the tests show other problems with your baby.

Some of these problems can be serious.

But some of these problems might not be serious.

If there is a problem you can talk to a special doctor who knows more about the problems.

They will give you information and support.

You can ask for that information in easy read format.
Your baby has Down’s syndrome.

Getting the news that your baby has Down’s syndrome can be quite upsetting.

If you are told that your baby has Down’s syndrome it is important to talk to people.

If you have a partner they might not feel the same as you.

It is important to talk to each other about how you feel.

It is okay to feel the way you do. Your partner’s feelings are okay too.

Everyone feels different.

You are not alone and many other parents have felt the same as you.

Talking to other parents with children with Down’s syndrome can be helpful and comforting.

They will be able to answer lots of your questions.

There is also a list of helpful organisations you could talk to in the back of this book.
Most babies with Down’s syndrome grow up as well-loved members of their families. Just like any other baby.
You do not have to go through this process on your own.
You talk to an advocate about this if you would like support. Advocacy services are usually free.
Find out if there is an advocacy service in your area and ask for support.

**What do I do now?**

If you discover that your baby has Down’s syndrome you have three choices.

It is important to remember that this is your decision.

1. You can choose to keep your baby.
2. You can choose to have your baby adopted.
3. You can choose to have an abortion.
• You can choose to keep your baby.

Find out who will be your ‘lead carer’.

This is someone you can ask for support.

You might want to use the time before the baby is born to get used to the news.

You might want to make different plans.

You might want to find out more about Down’s syndrome.
You can talk about this with your midwife or lead carer. You can also talk to the Down’s syndrome association about making plans for your baby. The number is in the back of this book.

Going to antenatal classes with other parent’s whose baby does not have Down’s syndrome might be hard for you. Some people decide not to go to those classes and need to find other ways to prepare.
• You can choose to have your baby adopted.

You might not feel that you are ready to bring up a child with Down’s syndrome.

If you don’t you could choose to have your baby adopted.

This means that after your baby is born, your baby would go and live with other people, usually a couple.

These people would be your baby’s adopted parents.

You may not see your baby again. But you would have a chance to say goodbye.

You might be able to keep in touch with the parents to get news of how the baby is doing.
• You can choose to have an abortion.

Abortion is sometimes called a termination.

This means that the pregnancy is ended, or terminated.

After an abortion you will not be pregnant any more.

You will not have a baby.

This is a big decision and it is important that you make the right choice for you.

Your doctor and midwife will offer you support.

Talk to people close to you. This could be your family, partner or advocate.
Before an abortion you have a baby growing in your womb.

After an abortion there is no baby growing in your womb.
The next few pages are about having an abortion.

Some people might find it upsetting to look at these pages.

You should look at them if you are thinking about having an abortion.

Look at these pages with someone you know or trust.

Ask your doctor, nurse or another member of staff to find someone to talk about this with you.

This person could be the local learning difficulties nurse or an advocate.

You can find your local learning difficulties nurse by calling the Duty Social Worker at the Council.

The number will be in your phone book.
What will happen if I have an abortion?

There are different ways that women can have abortions.
What will happen will depend on how long you’ve been pregnant.
There are medical abortions and surgical abortions.
You might be offered a choice but not always.

When a baby is still growing in the womb people call it a fetus.
You will see the word fetus a lot over the next few pages.
Medical abortions can happen when you are 9 – 20 weeks pregnant.
You will be given special drugs that cause a miscarriage.
A miscarriage is when the fetus comes out but it is not alive.
This is a process similar to giving birth.
You will usually have to stay in the hospital or clinic overnight and sometimes longer.
Surgical abortions

The type of surgical abortion you have will depend on how long you’ve been pregnant.

There is ‘vacuum aspiration’ and ‘surgical dilation and evacuation’ or D&E.

Most hospitals only do vacuum aspiration up to 13 weeks of pregnancy.

Between 14 and 21 weeks you can have ‘surgical dilation and evacuation’ or D&E.

Vacuum aspiration

This means removing the fetus with a suction pump.

You might be offered a choice of pain relief.

Usually you will be given special drugs to make you go to sleep when this happens.

This is called a ‘general anaesthetic’.

People usually go home the same day.
Surgical dilation and evacuation or D&E

This is done under a general anaesthetic. This means you will be asleep when it happens.

First they will gently stretch your cervix.

Your cervix leads from your vagina to your womb.

They will then use a special tool called forceps.

The doctor will use the forceps to remove the fetus.
Abortions after 21 weeks

Abortions after 21 weeks are quite rare.

Having an abortion after 21 weeks means going through a process similar to giving birth.

You might be given some medication to make you feel sleepy while it happens.

The doctors may give the fetus an injection.

This stops the heart so that the fetus it is not born alive.

The doctors then give you special drugs to induce labour.

This means making the fetus come out. It is similar to giving birth.

After the abortion.

Your doctor will give you a telephone number in case you have any problems.

You will also be asked to come back and see the doctor so that he can check that everything is okay.
Your feelings

Different people have different feelings after having an abortion.

If you have a partner they might not feel the same as you.

It is important to talk to each other about how you feel.

It is ok to feel the way you do. Your partner’s feelings are ok too.

Everyone feels different.

You can talk to your doctor or someone you trust about how you feel.

It is important that you get support.

Remember you are not on your own and lots of other people feel the same as you.
Some people like to talk to others about their feelings
Contraception

There are things that you can do if you don’t want to be pregnant again.

Using a condom when you have sex means you probably won’t get pregnant.

Condoms also protect you from sexually transmitted diseases.

There are also tablets that you can take and other things you can do to stop you getting pregnant.

Only condoms will protect you from sexually transmitted diseases.

To find out more you can call Sexual Health Direct on 0845 310 1334

You can also call the Family Planning Association (fpa) on 0845 122 8690

they are open from 9am until 6pm Monday to Friday.
What if I am not happy about my care.

If you are unhappy about anything that has happened at the doctors or at the hospital you can make a complaint.

NHS Direct can talk to you about complaints on 0845 4647.

You can also contact your local PALS (Patient Advice and Liaison Service) for advice and support when making complaints.

The number will be in your phone book.
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My Midwife’s address and phone number is:

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My next appointment with my Midwife is on:

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Useful organisations

The Down’s Syndrome Association
Langdon Down Centre
2A Langdon Park
Teddington
TW11 9PS
Tel: 0845 230 0372
www.downs-syndrome.org.uk

Antenatal Results and Choices (ARC)
73 Charlotte Street
London
W1T 4PN
Tel: 020 7631 0285
www.arc-uk.org

Contact a family
16 Strutton Ground
London
SW1P 2HP
0808 808 3555
www.cafamily.org.uk

MENCAP
123 Golden Lane
London
EC1Y 0RT
0808 808 1111
www.mencap.com
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The Elfrida Society publish and produce accessible information on a range of subjects.

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