

# Screening for Down's, Edward's and Patau's Syndromes in Twin Pregnancies

## Patient Information

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## Screening for Down's (T21) Edward's (T18) and Patau's (T13) Syndromes in Twin Pregnancies

All women who choose to have their baby in Wigan, including women who are having twins, are offered screening for T13, T18 and T21. General information about these syndromes and the screening tests for the conditions can be found in the UK National Screening Committee's (UK NSC) information booklet "Screening tests for you and your baby" available from your midwife or your doctor. It is also available to download in English and in other languages at: <https://www.gov.uk/government/publications/screening-tests-for-you-and-your-baby-description-in-brief>

Choosing whether or not to have the screening test is an important decision for you and your babies. This leaflet contains **additional** information you will need to consider when making a decision about whether to have screening when you are having twins.

### Choosing whether or not to have T13/18/21 screening

- You may wish to consider how you feel about having one or both babies with any of these syndromes.
- How important is it for you to know whether they have a syndrome before they are born?
- Some people decide not to have any tests.
- Some people choose to have tests so they can prepare themselves and find out more about the condition.
- Other people choose to have tests because they would decide to have a selective termination of one baby or terminate the whole pregnancy if both babies are affected.

If you are expecting **monochorionic twins** (MCDA) they will be identical, and they will both have the same chromosomes and genes. If your pregnancy is affected, both babies will have the same syndrome. If the twins each have their own placenta and are the same sex they may also be identical. If you decide to have the test you will be given one result for the whole pregnancy.

If you are expecting **dichorionic twins** (DCDA) they will each have their own placenta and are not identical. The chance for each baby will be considered individually. This means that if you decide to have the test you will be given a separate result for each baby. In very rare cases both babies may be affected and have a syndrome.

You may be faced with one baby having a lower chance result and one baby having a higher chance result.

## Difficult Decisions

Making decisions about what to do with the screening test information can be difficult. This decision can be even more difficult if you are faced with a different result for each baby.

**Before** you decide whether or not to have the screening test you might want to think about the following possible outcomes:

- What would I do if only one baby has one of the syndromes?
- Would I consider having a selective termination of the affected baby knowing that there was a chance I might miscarry and lose the unaffected baby?
- Do I think I would be able to cope psychologically for the rest of the pregnancy knowing that one of my babies was affected by T13, T18 or T21 and the other was unaffected?
- How would I feel about bringing up one child with a syndrome with the other one not affected?

We understand that these decisions are very difficult so please feel free to discuss your thoughts with your midwife or the screening midwife at the hospital.

## The Test

The combined test is offered to women expecting twins. This test involves both a blood test and an ultrasound scan and can be carried out between 11 weeks + 2 days and 14 weeks + 1 day of your pregnancy.

The combined test is explained in more detail in the UK NSC leaflet called “Screening tests for you and your baby”.

If you are more than 14 weeks and 1 day at your first scan a quad test would be offered but this can only test for Down’s syndrome, and is not as effective as combined screening. T13/18 screening would be offered via the 18-20+6 week scan.

## How many women receive a higher risk result?

The chance of chromosome problems increase with maternal age and your age will be used as part of the calculation. Overall, about 1 in 35 women (3%) who choose to have a combined screening test have a higher chance result, but this does not mean that the baby has T13, T18 or T21. The quad test performs differently in twin pregnancies and the screening midwife will discuss this with you if you are unable to have a combined screen. If you have conceived through IVF it is important to tell your midwife if you used frozen embryos or donor eggs as this information will be required in order to calculate the chance of the babies having T13, T18 or T21.

## What happens next if I have a higher chance result?

If you receive a higher chance screening test result for any of the syndromes you will be offered a **Diagnostic Test**. A specialist midwife or doctor will discuss your options and give you information about the diagnostic tests available.

Diagnostic tests give definite answers unlike screening tests. Having a diagnostic test is the only way of establishing whether one or both of your babies are affected. It is your decision whether to have a diagnostic test or not.

After you have been given the information and an opportunity to ask questions, you will be given time to make up your mind about what to do next. The “Screening tests for you and your baby” booklet explains in detail about the two types of diagnostic tests. These are called chorionic villus biopsy/sampling and amniocentesis.

There are a few differences you will need to consider because you are expecting twins; these are explained below.

### Chorionic Villus Biopsy (CVB) or Chorionic Villus Sample (CVS)

This test is usually carried out between 11 and 14 weeks of pregnancy. A small sample of tissue is taken from the placenta of each baby. If the babies share one placenta and so are identical, they will also have the same chromosomes; therefore only one sample will be taken. This procedure has a 2–3% risk of miscarriage in twin pregnancies. This means that for every 100 women expecting twins, who have a CVS test, 2 or 3 will miscarry one or both babies.

### Amniocentesis

This test is usually carried out from 15 weeks of pregnancy. A sample of amniotic fluid is taken from around each baby. If the babies share one placenta and so are identical, they will also have the same chromosomes; therefore only one sample of amniotic fluid is taken. This procedure has a 2–3% risk of miscarriage in twin pregnancies. This means that for every 100 women expecting twins, who have an amniocentesis, 2 or 3 will miscarry one or both babies.

If you choose to have a diagnostic test you will be referred to the Fetal Medicine Unit at St Mary’s hospital, Manchester where the doctors have specialist experience of these procedures in twin pregnancies.

The diagnostic tests count the pairs of chromosomes in the baby’s cells and can give you a definite result. You will receive results for Down’s, Edward’s and Patau’s syndromes, regardless of which was higher chance.

## What are the possible results from a diagnostic test?

### 1) Neither of the babies has a syndrome.

This is the result most women with a higher chance of a syndrome receive.

### 2) One baby has T13, T18 or T21

A small number of women who have a diagnostic test will be faced with the result that one baby has a syndrome and one baby does not have a syndrome. These women will then have to consider the following options before they make a decision:

- Some women will decide to continue with the pregnancy. They will make plans and prepare to give birth to one baby affected by the syndrome and one baby unaffected by the syndrome.
- Some women will decide they do not want to continue with the pregnancy and have a termination of the whole pregnancy.
- Some women will decide they want to consider a selective termination of only the baby affected by the syndrome. This is a complex procedure, known as feticide, which carries risks for the whole pregnancy. The risks will be fully discussed in detail with you by a specialist team at St Mary's hospital.
- Some women will decide to continue with the pregnancy but feel that they cannot care for the child affected by the syndrome themselves. They may consider adoption or fostering for the affected baby.

### 3) Both babies have T13, T18 or T21

A very small number of women who have a diagnostic test will be faced with the result that both babies are affected by one of the syndromes. These women and their partners will then have to consider the following options before they make a decision:

- Some women will decide to continue with the pregnancy. They will make plans and prepare to give birth to two babies affected by a syndrome.
- Some women will decide they do not want to continue with the pregnancy and have a termination of the whole pregnancy.
- Some women will decide to continue with the pregnancy but feel that they cannot care for the babies themselves and consider adoption or fostering.

## Reaching your decision

If you are faced with these results, you will be given information and support to help you reach the right decision for you and your family. You will have the opportunity to discuss all the options with health care professionals and you will be offered information and support. You will be offered details of other organisations outside the health service that can provide additional information and support. You will have time to decide what to do and the health care professionals caring for you will support you whatever decision you make.

## Further information

### Twins and Multiple Births

#### Multiple Births Foundation (MBF)

Website: [www.multiplebirths.org.uk](http://www.multiplebirths.org.uk)

Email: [mbf@imperial.nhs.uk](mailto:mbf@imperial.nhs.uk)

Telephone: 020 3313 3519

### Twins and Multiple Births Association (TAMBA)

Website: [www.tamba.org.uk](http://www.tamba.org.uk)

Telephone: 01483 304 442

Twin line: 0800 138 0509

Email: [enquiries@tamba.org.uk](mailto:enquiries@tamba.org.uk)

(Office hours are 10am to 4pm Monday to Friday)

### Down's Syndrome

#### Contact

Website: <https://contact.org.uk>

Freephone helpline: 0808 808 3555

Email: [info@contact.org.uk](mailto:info@contact.org.uk)

This free helpline for parents and families is open from 9:30 to 5:00 pm, Monday to Friday.

### Down's Syndrome Association

Website: [www.downs-syndrome.org.uk](http://www.downs-syndrome.org.uk)

Telephone: 0333 1212 300

### Down's Syndrome Medical Interest Group

Website: [www.dsmig.org.uk](http://www.dsmig.org.uk)

An information service for healthcare professionals

## **Edward's and Patau's syndromes**

### **SOFT UK**

Support organisation for trisomy 13/18

Website: [www.soft.org.uk](http://www.soft.org.uk)

Telephone: 0121 351 3122

### **Screening:**

#### **Antenatal Results and Choices (ARC)**

Website: [www.arc-uk.org](http://www.arc-uk.org)

Helpline: **0845 077 2290** or **0207 713 7486** via mobile

Email: [info@arc-uk.org](mailto:info@arc-uk.org)

## **Contact**

### **Antenatal Screening Midwife**

Wrightington Wigan & Leigh NHS Trust

Thomas Linacre Centre, Suite 4

Parson's Walk

Wigan

WN1 1RU

Tel: 01942 774702 or 01942 774700

Mob: 07500 607050

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## Comments, Compliments or Complaints

The Patient Relations/Patient Advice and Liaison Service (PALS) Department provides confidential on the spot advice, information and support to patients, relatives, friends and carers.

## Contact Us

Tel: 01942 822376 (Monday to Friday 9am to 4pm)

The Patient Relations/PALS Manager  
Wrightington, Wigan and Leigh NHS Foundation Trust  
Royal Albert Edward Infirmary  
Wigan Lane  
Wigan WN1 2NN

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## Ask 3 Questions

Become more involved in decisions about your healthcare. You may be asked to make choices about your treatment. To begin with, try to make sure you get the answers to three key questions:

1. What are my options?
2. What are the pros and cons of each option for me?
3. How do I get support to help me make a decision that is right for me?



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## How We Use Your Information

For details on how we collect, use and store the information we hold about you, please take a look at our “how we use your information” leaflet which can be found on the Trust website:  
[https://www.wwl.nhs.uk/patient\\_information/leaflets/](https://www.wwl.nhs.uk/patient_information/leaflets/)

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This leaflet is also available in audio, large print, Braille and other languages upon request. For more information please ask in the department/ward.

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