Wrightington, Wigan and
Leigh Teaching Hospitals
NHS Foundation Trust

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

Patient Information

Maternity

The Patient Information Leaflets page on the Trust website is available on the link: https://www.wwl.nhs.uk/patient-information-leaflets or scan the QR code.

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Our Values People at the Heart Listen and Involve Kind and Respectful One Team

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 leaflet “Screening tests for you and your baby,” which is 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 to have the 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 that 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 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 Thomas Linacre Centre.

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 “Screening tests for you and your baby” information leaflet.

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 chance result?

The chance of chromosome problems increases 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 contacted by a specialist midwife, who will discuss your options and give you information about further tests available; these include a more accurate screening test or diagnostic tests.

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 definitely affected. It is your decision whether to have a further 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 following link explains in detail about the two types of diagnostic tests. These are called chorionic villus biopsy/sampling and amniocentesis.

https://www.gov.uk/government/publications/cvs-and-amniocentesis-diagnostic-tests-description-in-brief

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

Non-Invasive Prenatal Test (NIPT)

This is a more accurate method of screening and is performed by looking for placental DNA in a sample of your blood. Whilst this test is not 100%, it will give a more accurate estimation of the chance of your babies having Down's, Edward's or Patau's syndromes than the combined or quad test. However, sometimes it is not possible to get a result, and the test has to be repeated. Occasionally a result cannot be obtained at all. There is no risk of miscarriage with this option.

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 that 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 that 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.

Contact

Antenatal Screening Midwife

Wrightington Wigan & Leigh NHS Trust
Thomas Linacre Centre, Suite 4
Parson's Walk
Wigan
WN1 1RU
Tel: 0300 707 5702
Mob: 07920 018461 or 07920 775701

Useful information

Twins and Multiple Births

Multiple Births Foundation (MBF)
Website: www.multiplebirths.org.uk
Email: mbf@bcu.ac.uk
Telephone: 07360 735 050

Twins Trust (formerly TAMBA)
Website: https://twinstrust.org
Twin line: 0800 138 0509
(Available 10am to 1pm and 7pm to 10pm Monday to Friday)

Down’s Syndrome

Down’s Syndrome Association
Website: www.downs-syndrome.org.uk
Telephone: 0333 1212 300
Email: info@downs-syndrome.org.uk

Down’s Syndrome Medical Interest Group

Website: 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
Telephone: 0300 102 7638Email: support@soft.org.uk

All disabilities

Contact

Website: https://contact.org.uk

Freephone helpline: 0808 808 3555

Email: helpline@contact.org.uk

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

Screening:

Antenatal Results and Choices (ARC)

Website: www.arc-uk.org
Helpline: **0845 077 2290** or **0207 713 7486** via mobile
Email: info@arc-uk.org

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 until 4pm)

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

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 positives and negatives of each option for me?
3. How do I get support to help me make a decision that is right for me?

How We Use Your Information

For details on how we collect, use, and store the information we hold about you, please see patient information leaflet, Ref. **Corp 006** How we use your information, this can be found on the Patient Information Leaflets page on the Trust website, see details on the front cover.

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

Call 111 first when it’s less urgent than 999.

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