

AMNIOCENTESIS INFORMATION FOR PATIENTS

INTRODUCTION

This leaflet has been provided to help answer some of the questions you may have about AMNIOCENTESIS. The screening advisor or doctor will discuss the procedure thoroughly, including risk and benefits, before you make any decisions.

It is important that you understand that only YOU can decide whether or not you want to have this test.

WHY HAVE I BEEN OFFERED THIS TEST?

Amniocentesis is usually offered to women whose Combined or Triple Test Screening result has shown that there is an increased chance of them having a baby with Down's Syndrome (A chromosome abnormality).

You may also be offered an Amniocentesis test if:

- there is an inherited condition in your family such as Cystic Fibrosis or Sickle Cell disease (in which case, you may require specialist counselling prior to your procedure)
- your 20 week scan (Anomaly scan) has shown your baby to have an increased chance of a chromosome problem

Amniocentesis is a DIAGNOSTIC test, which means it will give you a definite answer.

NOT ALL WOMEN ARE OFFERED THIS TEST

WHAT IS DOWN'S SYNDROME?

The incidence of Down's Syndrome is around 1 per 600-800 births; anyone can have a baby with Down's Syndrome, regardless of age, family history or ethnic background. However, a women's risk of having a baby with Down's Syndrome increases with age.

There is no such thing as a typical person with Down's Syndrome. As with all people, they vary a lot in appearance, personality and ability. Individuals with Down's Syndrome have learning difficulties, some are more affected than others and the majority of individuals require long term help and support. Individuals with Down's Syndrome may also have other related health problems such as heart problems, reduced hearing and vision and obesity. Many of these problems are identified and treated as early as possible. Most

individuals with Down's syndrome live to be 50 years of age. However, Alzheimer's disease may affect these individuals at an earlier age than in the general population.

HOW IS IT CAUSED?

There are tiny structures called CHROMOSOMES in each cell of our body. The genetic information carried by our chromosomes determines how we develop (they are the building blocks of information). An individual has 23 pairs of chromosomes in each cell. However an individual with Down's Syndrome has an EXTRA Chromosome 21, sometimes known medically as Trisomy 21. This extra chromosome cannot be removed from the cells and so there is NO cure for this condition.

For more information about the reality of raising a child with this condition, you may wish to contact the Down's Syndrome association. You can find these details on the back of this booklet.

WHAT IS AMNIOCENTESIS?

Amniocentesis is a diagnostic test performed by an experienced doctor anytime after 15 weeks of pregnancy. Amniocentesis is an invasive test, which means it can increase your risk of miscarriage by 1% (1 woman out of 100 women having Amniocentesis will miscarry). We do not know why this happens, however it is usually within 2 weeks of the procedure (following the procedure you will be given information on the signs and symptoms, which might indicate a miscarriage and the relevant contact numbers should you be concerned).

The doctor will go through the consent form with you prior to the procedure. The doctor will then cleanse your abdomen (tummy). A fine needle will then be passed through your abdomen (tummy), under the guidance of continuous ultrasound scanning, and into the amniotic fluid surrounding your unborn baby (this fluid contains cells from your baby). A small sample of this fluid is then obtained (usually 15mls) and sent to the Cytogenetics Lab in Oxford for analysis.

WILL IT HURT?

Most women say that having an Amniocentesis is uncomfortable rather than painful. Some say there is a sharp feeling as the needle goes in with a pressure feeling when the needle comes out. You can take Paracetamol for any discomfort (please remember, however, that you can only take a maximum of 8 tablets in 24 hours).

BEFORE AND AFTER THE PROCEDURE

On the day of your procedure it is important that you continue to eat and drink as normal to avoid feeling faint. You do not need to have a full bladder for this procedure. Following the procedure, as long as you are feeling fine, you may go home and rest for at least 48 hours. It is important that you bring someone with you to the hospital for support and help with your journey home.

WHAT ABOUT MY RESULTS?

Before you leave the hospital the screening advisor will check your contact numbers and arrange with you as to how you wish to receive your results. Results are usually given by phone.

Amniocentesis can only give a result that reveals if your baby has Down's Syndrome. The test CANNOT tell you if your baby will be mildly or severely affected.

Full Result / Karyotype (2-3 weeks): This result involves growing the baby's cells so that they can be examined under a microscope. This test examines all 23 pairs of chromosomes and confirms that they are all in number order with no extra or missing chromosomes, giving a definitive result. (Please note, however, that single gene alterations such as Cystic Fibrosis, micro deletions and other small changes in chromosomes will not be detected in this test). This test can also reveal if you're having a boy or girl and you will be given this information if you have requested it. Your results will be posted to you by the laboratory if they are "normal". If there is a problem you will receive a call from your Screening Team to arrange a hospital appointment to discuss your results and options.

CAN I GET MY RESULTS ANY SOONER?

YES. Rapid result / Amnio PCR (3 working days): It is now possible to have additional laboratory analysis that will give you a quick result. The test examines only **3** out of the 23 pairs of chromosomes, numbers **13** (Patau's Syndrome), **18** (Edward's Syndrome) and **21** (Down's Syndrome). This test is 99.8% accurate so can be reassuring while you are waiting for your full result. This test is only available privately at a cost of around £105.

ARE THESE TESTS RELIABLE?

Occasionally, either PCR or a Full Karyotype does not give a clear result or is unable to be processed. This is rare (Amniocentesis 1:2000) but if it happens your screening team will contact you and resolve this on an individual basis, which may include having another Amniocentesis.

WHAT IF THERE IS SOMETHING WRONG WITH MY BABY?

If the results show that your baby has a chromosomal abnormality, your doctor and screening team will discuss this with you, in detail. If you wish, they can arrange for you to be seen by the genetic nurse specialist. When you are deciding what to do, you need to consider what is best for you and your family. The screening team will be happy to talk through any worries you may have and they will be fully supportive of any decision you make. We also offer the option of seeing our specialist counsellor.

WHERE CAN I GET MORE INFORMATION ABOUT AMNIOCENTESIS TESTS, THE DIFFERENT CONDITIONS THEY MIGHT DETECT AND THE CHOICES I HAVE?

Antenatal Results and Choices (ARC)

www.arc-uk.org

0207 631 0285

Down's Syndrome Association (DSA)

www.downs-syndrome.org.uk

0845 230 0372

S.O.F.T UK (support organization for Edward's and Patau's Syndrome)

www.soft.org.uk

0121 351 3122

Contact a Family (CAFAMILY)

www.cafamily.org.uk

0808 808 3555

USEFUL TELEPHONE NUMBERS

Antenatal Screening Team Wexham Park Hospital

01753 633301

Ward 21 Wexham Park Hospital

01753 634516

Labour Ward Wexham Park Hospital

01753 634520

If you would like a copy of this leaflet on audiotape, in large print or translated, please telephone 01753633939'

اگر آپ کو اس کتابچے کی کاپی اڈیو ٹیپ پر، یا بڑے حروف یا پھر آپ کی زبان میں ترجمہ کی ہوئی درکار ہو

تو برائے مہربانی کسی انگریزی بولنے والے سے اس نمبر پر فون کروائیے 01753633939

'Daca doriti sa primiti continutul acestui fluturas pe caseta audio, tiparit cu caractere mai mari, sau daca doriti ca textul sa va fie tradus, va rugam cereti unei persoane care vorbeste engleza sa sune la telefon 01753 633939'

Haddii aad Rabto Nuqulka ama koobiga Waraaqdan oo ah Cajalad , Farwaaweyn ama Turjuman Fadlan Weyddii Qof ku hadla afka ingiriisiga in uu soo Telifooniyoo Lambarkan : 01753-633939.

अगर आपको इस पत्र पर दी गई जानकारी टेप पर रिकार्ड की हुई या आपकी भाषा में अनुवाद करके, या फिर बड़े अक्षरों में लिखी हुई चाहिए तो किसी अंग्रेजी बोलने वाले से कह कर 01753 633 939 पर फ़ोन करवाएँ।

ਅਗਰ ਇਸ ਪਰਚੇ ਵਿਚ ਦਿਤੀ ਹੋਈ ਜਾਣਕਾਰੀ ਤੁਹਾਨੂੰ ਟੇਪ ਤੇ ਰਿਕਾਰਡ ਕੀਤੀ ਹੋਈ ਜਾ ਅਨੁਵਾਦ ਕਰਕੇ ਜਾ ਫਿਰ ਵੱਡੇ ਅਖਰਾਂ ਵਿਚ ਲਿਖੀ ਹੋਈ ਚਾਹੀਦੀ ਹੋਵੇ ਤਾਂ ਕਿਸੇ ਅੰਗਰੇਜ਼ੀ ਬੋਲਣ ਵਾਲੇ ਨੂੰ ਕਹਿ ਕੇ 01753 633 939 ਤੇ ਫ਼ੋਨ ਕਰਾਓ।

Je_eli chcesz otrzymac niniejsza ulotke na tasmie audio, w postaci du_ej czcionki lub w innym jezyku, zadzwon na numer 01753 633939.

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Legal Notice

Please remember that this leaflet is intended as general information only. We aim to make the information as up to date and accurate as possible, but please be warned that it is always subject to change. Please therefore always check specific advice on any concerns you may have with your doctor.

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