

PATIENT INFORMATION

Following a Higher Chance Result

(Maternity Screening Tests)

Following a Higher Chance Result

[Following your Down Syndrome screening test result](#) (Pages 1-2)

[Following you Edward's/ Patau's screening test result](#) (Pages 3-4)

Following your Down Syndrome screening test result

Your result has come back within the higher chance range of your baby having Down Syndrome.

For many people this will not have been anticipated and you may not have thought about what you want to do now. In this section there is a list of common questions that people ask, and some answers which may help you to decide what you would like to do.

What does my screening test actually mean?

The test you have had has not told you anything definite about your baby. Everybody who has a screening test will be given a result expressed in the form of their 'chance' of having a baby with Down syndrome.

The reason we offer the test is to identify a group of women to whom we offer a further non-invasive blood test (NIPT) or a 'diagnostic' test (chorionic villus sampling or amniocentesis). These diagnostic tests can tell you if your baby has Down Syndrome. Anyone who has a high chance result is offered one of these tests and it is your choice if you wish to have further testing. Only a very small percentage of babies in the higher chance group will have Down Syndrome. For example, if you were told your chance is 1:100 this represents only a 1% chance of this being the case. If your chance is 1:10 there is a 10% chance. It is also true that there will still be some babies with Down Syndrome in the lower chance group who have not been identified by the screening process.

What do most women do in my situation?

Every women's circumstances and life experience is different. There is no right or wrong way to proceed through the screening process. The important thing is to be able to have all the information and support you need to make the right decision for you.

It may not be possible for you to know at this stage what you would do if you found out that your baby did have Down Syndrome. Many couples find that until they are faced with that reality it is impossible to really know how they would feel.

For this reason, we recommend you come back to the hospital to discuss your result with a midwife who specialises in screening. Also, ARC (antenatal results and choices) offer a telephone help line to help people with their decision making and the Down Syndrome Association will send you information on request (see contact numbers at end of leaflet).

What will happen if the test shows my baby has Down Syndrome?

You will be offered an appointment as soon as possible to come and discuss the result with the specialist midwife at the hospital. An appointment with a Paediatrician is also available if you would like it. You can make the decision about what to do next in your own time once you have all the information you need. At the hospital we are able to give you booklets produced by ARC which may help you with your decision making. Again, many people find their helpline service useful.

What are my options if I wanted to end the pregnancy?

The ARC booklet gives you some detailed information about the options available. If you are further than 14 weeks pregnant, then at this hospital we arrange for you to have an induced miscarriage as this has less chance of causing any damage to the neck of the womb or perforation to the uterus, which could cause you problems with subsequent pregnancies. If you are earlier than 14 weeks it is possible to have a surgical operation to end the pregnancy.

Useful organisations and websites

Antenatal results and choices: www.arc-uk.org Tel: 0207 631 0285

Down's Syndrome Association: www.downs-syndrome.org.uk Tel: 0845 230 0372

Positive about Down Syndrome
<https://positiveaboutdownsyndrome.co.uk/nobodytoldme/>

PATIENT INFORMATION

Following your Edward's / Patau's Screening Result

Your result has come back within the higher chance range of your baby having Edward's (Trisomy 18) or Patau's Syndrome (Trisomy 13).

For many people this will not have been anticipated and you may not have thought about what you want to do now. In this section there is a list of common questions that people ask, and some answers which may help you to decide what you would like to do.

What does my screening test actually mean?

The test you have had has not told you anything definite about your baby. Everybody who has a screening test will be given a result expressed in the form of their 'chance' of having a baby with either of these syndromes.

The reason we offer the test is to identify a group of women to whom we offer a further non-invasive blood test (NIPT) or a 'diagnostic' test (chorionic villus sampling or amniocentesis). These diagnostic tests can tell you if your baby has Edward's or Patau's syndrome. Only a very small percentage of babies in the higher chance group will be affected by Edward's or Patau's Syndrome. For example, if you were told your chance is 1:100 this represents only a 1% chance of this being the case. If your chance is 1:10 there is a 10% chance. It is also true that there will still be some babies with one of these syndromes in the lower chance group who have not been identified by the screening process.

What do most women do in my situation?

Every woman's circumstances and life experience is different. There is no right or wrong way to proceed through the screening process. The important thing is to be able to have all the information and support you need to make the right decision for you.

It may not be possible for you to know at this stage what you would do if you found out that your baby did have Edward's or Patau's Syndrome. Many couples find that until they are faced with that reality it is impossible to really know how they would feel. For this reason we recommend you come back to the hospital to discuss your result with a midwife who specialises in screening. Also, ARC (antenatal results and choices) offer a telephone help line to help people with their decision making.

What will happen if the test shows my baby has Edward's or Patau's Syndrome?

You will be offered an appointment as soon as possible to come and discuss the result with the specialist midwife at the hospital. An appointment with a Paediatrician is also available if you would like it. You can make the decision about what to do next in your own time once you have all the information you need. At the hospital we are able to give you booklets produced by ARC which may help you with your decision making. Again, many people find their helpline service useful.

What are my options if I wanted to end the pregnancy?

The ARC booklet gives you some detailed information about the options available. If you are further than 14 weeks pregnant, then at this hospital we arrange for you to have an induced miscarriage as this has less chance of causing any damage to the neck of the womb or perforation to the uterus, which could cause you problems with subsequent pregnancies. If you are earlier than 14 weeks it is possible to have a surgical operation to end the pregnancy.

Useful organisations and websites

Support organisation for Trisomy 18/13 <http://www.soft.org.uk/>

Antenatal results and choices: www.arc-uk.org Tel: 0207 631 0285

For further assistance or to receive this information in a different format, please contact the department which created this leaflet.