

## Downs Syndrome - Counselling Parents - Full Clinical Neonatal Guideline

Reference no.: NIC MIS 03/ June 17/v003

### 1. Introduction

To ensure a standardised approach when counselling parents with Down's syndrome

### 2. Aim and Purpose

For all staff to ensure that parents are given appropriate information about Down's syndrome and chromosome analysis done as early as possible.

### 3. Main body of Guidelines

When Down's syndrome is suspected in a newborn infant it can be a difficult situation to approach. However it is important to get right. The term Mongol is not appropriate, upsets parents and should not be used. The features of an "ideal service", based on experience of parents with a Down's syndrome child include the following: -

1. Parents should be told the diagnosis by a Consultant Paediatrician.
2. Both parents and the baby should if at all possible be present, and they should be holding, or touching the baby.
3. A quiet room with privacy should be used.
4. Not more than two members of staff should be present.
5. Explanation should be straightforward and at a pace the parents set.
6. There should be time for parents to be alone together.
7. There should be time for parents to ask questions.
8. The person who broke the news should come back and visit the parents. (Ref. I Byrne).
9. The person who counsels the parents should contact the family doctor as soon as possible.

Although there is no wish to delay the initial discussion with parents, it is clear that to fulfil the important factors above this has to be "stage managed" to a certain extent.

The following are **local guidelines**, which should help us to provide as near as possible an "ideal service".

1. Labour suite does not provide the right environment for counselling. It should be done on the post natal ward, in a quiet room, with both parents present where possible.
2. The counselling will be carried out by a Consultant Paediatrician, usually

Dr M Ratnayaka, Dr N Ruggins, Dr J McIntyre, Dr Bala Subramaniam, Dr Gitika Joshi, Dr Bemigho Etuwewe, Dr Shalini Ojha. It may be appropriate for a middle grade Paediatrician to be present to act as a medical link.

3. Counselling of parents should take place as soon as practicable, usually within 24 hours after birth.
4. If parents notice problems, or raise concerns with the baby themselves, then these must be responded to at that time by the most senior member of the paediatric staff available, even if this occurs on the labour suite in non-ideal circumstances.
5. The midwife caring for the mother/baby should also be present.
6. The initial counselling will be followed up by a repeat visit for further discussions and explanations and early out-patient review once discharged.
7. Ask parents if they would like to speak to other parents with a Down's syndrome child.
8. Provide parents with written information leaflets that are available about Down's syndrome, to read at their leisure. The Down's Syndrome Association website is a reliable and useful source of information ([www.downs-syndrome.org.uk/](http://www.downs-syndrome.org.uk/)). Local contact/information is available at Downs Syndrome Derby (email: [contact@dsderby.org](mailto:contact@dsderby.org); website: [www.dsderby.org](http://www.dsderby.org)). Allow time for discussion of any issues raised by the leaflets.
9. The person who counsels the parents should contact the family doctor as soon as possible. They will also need to arrange appropriate follow. This will be according to individual needs but will usually include arrangements for early echocardiogram and liaison with the Specialist Health Visitor (Sally Neeley) and Dr Hobday who lead the community based follow up in the Ronnie MacKeith Centre.

#### **4. References (including any links to NICE Guidance etc.)**

- Byrne E, Sloper P, Cunningham C Families and their Children with Down's Syndrome : One feature in Common London: Routledge & Kegan Paul 1988.
- Guay Ong. Modern Midwife. July/August 1993.
- The Down's Syndrome Association: [www.downs-syndrome.org.uk/](http://www.downs-syndrome.org.uk/)

**5. Documentation Controls**

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