

# Management of Pregnancy

## when Down's syndrome has been diagnosed

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### **What this fact sheet does**

This fact sheet has been written to offer guidance to midwives, obstetricians and primary care teams about the ongoing management of pregnancy after a diagnosis of Down's syndrome. It explores the risks associated with such a pregnancy, and the possible associated congenital anomalies which may affect the fetus. The leaflet includes identifying and preparing for health issues which may require action to optimise the health and safety of the baby during pregnancy, labour, delivery, and in the neonatal period.

### **What this fact sheet does not do**

The aim of this fact sheet is to help support provision of appropriate medical management of the mother and fetus once a decision has been made to continue the pregnancy.

It does not attempt to cover antenatal screening or diagnostic tests for Down syndrome nor the decision making around continuation of the pregnancy.

It does not consider in any detail the information needs, counseling or emotional support that may be involved. Information for women on these issues can be found in resources below.

### **Issues relating to the pregnancy**

There is increased risk of the following in pregnancies with Down's syndrome:

#### **Prematurity**

The risk of prematurity in babies with Down's syndrome is increased, with mean length of gestation 38 weeks. This in part relates to the amount of surveillance undertaken, since babies with Down's syndrome are often small and earlier delivery may be recommended.

#### **CTG anomalies in labour**

Decisions on monitoring in labour should be based on the risks already ascertained in pregnancy. If the baby has shown signs of growth restriction, continuous monitoring should be recommended. Otherwise, decisions on monitoring should be in line with the NICE intrapartum care guideline.

## **Fetal Loss**

A fetus with Down's syndrome has an increased risk of miscarriage, intrauterine fetal death (IUFD), stillbirth and neonatal death. There are many causes of fetal loss, including those described below.

The rate of spontaneous fetal death in trisomy 21 between 12 weeks (when NT screening is carried out) and 40 weeks is about 30%.

The rate of spontaneous fetal death between 16 weeks (when second trimester maternal serum biochemical testing is carried out) and 40 weeks is about 20%.

The procedure related loss rate (following amniocentesis or Chorionic villous biopsy) is as for all pregnancies i.e. approximately 1%.

## **Issues relating to the Fetus**

### **Growth**

Mean birthweight in babies with Down's syndrome is lower than in the general population. Growth in the first trimester is similar to fetuses without Down's syndrome but weight gain slows in the last weeks of pregnancy, particularly after 38 weeks gestation. Growth restriction is also a risk factor for IUFD.

Regular growth scans are recommended at 28, 34 and 38 weeks.

Where the fetus is growing poorly there is a need to balance the risks of continuing pregnancy with poor fetal growth with the risks of prematurity (as for a pregnancy without Down's syndrome.)

As for any pregnancy reduced fetal movements are a sign of the fetus being in poor condition and should not be accepted as "typical for a baby with Down's syndrome." Mothers need to be reminded that babies should remain active even during late pregnancy and to report any reduction in fetal movements.

### **Hydrops**

This will be detected by ultrasound scans as above. If a mother presents with reduced fetal movements between scans a repeat scan for fetal wellbeing is advantageous.

The risk of fetal anaemia can be assessed using middle cerebral artery Doppler velocities on ultrasound scan.

If hydrops is seen, referral to a fetal medicine specialist is recommended.

Hydrops can be:

- Idiopathic
- Secondary to Transient Abnormal Myelopoiesis (TAM)
- Secondary to cardiac abnormality.

### **Transient Abnormal Myelopoiesis (TAM)**

TAM, a pre-leukemic condition that occurs in up to 10% of neonates with Down's syndrome, can present during fetal life with hepatosplenomegaly and hydrops. Detection in pregnancy should prompt referral to a fetal medicine specialist and an alert to the neonatal team for ongoing management.

## **Structural anomalies**

### **Congenital heart disease (CHD)**

40-60% of babies with Down's syndrome are born with CHD. All fetuses with a diagnosis of Down's syndrome should undergo fetal echocardiography (ECHO). If a CHD is detected, a Paediatric cardiology specialist will be called upon to give advice re implications and provide an action plan for care in the immediate postnatal period.

A normal fetal ECHO cannot rule out small septal defects, and failure of closure of fetal connections i.e. Patent Foramen Ovale (PFO) and Patent Ductus Arteriosus (PDA)) are not seen in utero. Postnatal ECHO is recommended for all babies born with Down syndrome in the neonatal period regardless of findings from fetal assessment.

### **Bowel Atresia**

This may be suspected either because the anomaly is visualised on scan or suspicion raised by the presence of polyhydramnios.

Atresias are not usually seen at the 18 to 20 week anomaly scan and may not be visible until the third trimester, but may be seen if further scans are undertaken as recommended above. Lower bowel atresias are less common and will not be detected by ultrasound.

When an atresia is suspected the neonatal team/paediatric surgeons should be forewarned so that they can plan neonatal management.

### **Brain**

Mild ventriculomegaly is a common antenatal finding – when it occurs in isolation does not necessarily prompt a search for an explanation but is more common in pregnancies with Down's syndrome.

### **Renal anomalies**

Renal pelvis dilatation is more common in Down's syndrome and may be indicative of obstructive nephropathy. The usual pathway for renal pelvis dilatation should be followed, with referral to paediatricians/ paediatric nephrologists to arrange post natal imaging where the threshold is passed.

## **Antenatal and Perinatal care**

### **Where should the pregnancy should be managed?**

Pregnancies affected by Down's syndrome should be managed in an obstetrician led unit.

### **What additional care is required?**

Parents expecting a baby with Down's syndrome may benefit from the input of Specialist paediatric teams relevant to any anomalies diagnosed during pregnancy, for post birth planning. They may also be offered the opportunity to meet clinicians from the local health services for children with Down's syndrome for discussion around health issues that need to be considered, developmental issues the baby may face and services to support them.

Parents should be given or signposted to further information about Down's syndrome, in the form of leaflets, books or online resources.

The opportunity to meet other families is generally welcomed.

## Birth planning should include:

- parental choices as for any pregnancy
- place of delivery
- time of delivery
- discussion of need for fetal monitoring
- Care required in the immediate postnatal period.

## Where should the baby be delivered?

Babies should be delivered in an environment where they have rapid access to specialist neonatal care if needed.

For those diagnosed with conditions likely to require surgery in the immediate neonatal period, delivery should be in a unit with access to neonatal surgery, so that separation of mother and baby can be avoided.

## Resources

DSA Leaflet for parents – Looking forward to your baby

[www.downs-syndrome.org.uk/download-package/9-continuing-pregnancy-with-a-diagnosis-of-downs-syndrome/](http://www.downs-syndrome.org.uk/download-package/9-continuing-pregnancy-with-a-diagnosis-of-downs-syndrome/)

Screening tests for you and your baby. UK National Screening Committee

<https://www.gov.uk/government/publications/screening-tests-for-you-and-your-baby-description-in-brief>

Down's Syndrome Association - New Parent Pack

[www.downs-syndrome.org.uk/download-package/new-parents-pack/](http://www.downs-syndrome.org.uk/download-package/new-parents-pack/)

Tell it right, Start it right – Royal College of Midwives accredited

Down's Syndrome Association Training for Midwives –

[www.downs-syndrome.org.uk/policy-and-campaigns/tell-it-right-start-it-right/](http://www.downs-syndrome.org.uk/policy-and-campaigns/tell-it-right-start-it-right/)

The 11-13+6 week scan Kypros H. Nicolaides Fetal Medicine Foundation 2004

[www.fetalmedicine.com/synced/fmf/FMF-English.pdf](http://www.fetalmedicine.com/synced/fmf/FMF-English.pdf)

Maternal age-specific fetal loss rates in Down syndrome pregnancies. Savva GM1, Morris JK, Mutton DE, Alberman E. Prenat Diagn. 2006 Jun;26(6):499-504. [www.ncbi.nlm.nih.gov/pubmed/16634111](http://www.ncbi.nlm.nih.gov/pubmed/16634111)

The National Down syndrome cytogenetic register

<https://www.qmul.ac.uk/wolfson/research-projects/current-projects/projects/national-down-syndrome-cytogenetic-register-ndscr.html>

Down Syndrome Medical Interest Group –DSMIG UK and Ireland

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

## In memory of Harvey Asaad

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### Down's Syndrome Association

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