DOWN'S
SYNDROME
ASSOCIATION

Our 'Tell it Right'® Top Tips

Last updated: August 2021

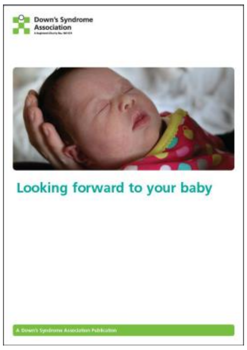
Sharing news that might be unexpected with prospective or new parents is probably one of the most important aspects of your role. We know that you will want to do this well and feel prepared and confident in answering any queries parents might have.

These tips will help healthcare professionals who are giving the diagnosis to 'Tell it Right'®.

At prenatal diagnosis

1. Telling the parents

- Face to face with both parents or with someone to support the mother. People may not take in all the information you give.
- Have accurate and balanced information about Down's syndrome to give to the parents
- Allow the parents plenty of time to absorb the information.
- Where appropriate, have the DSA resource 'Looking forward to your baby' ready to give to the parents (not a photocopy). This can be downloaded here: downs-syndrome.org.uk/LookingForwardToYourBaby/



Down's Syndrome Association

Looking forward to your baby

A Down's Syndrome Association Publication

2. Management of pregnancy

The Down's Syndrome Association and Down Syndrome Medical Interest Group UK & Ireland fact sheet 'Management of Pregnancy when Down's syndrome has been diagnosed' offers guidance to midwives, obstetricians and primary care teams about the ongoing management of pregnancy after a diagnosis of Down's syndrome. 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. downs-syndrome.org.uk/ManagementOfPregnancy/

Down's Syndrome Association

Management of Pregnancy

when Down's syndrome has been diagnosed

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Produced by Lucy Kean (Consultant Obstetrician) Lorna Parsons (Midwife, fetal care) and Liz Marder (Consultant Paediatrician) Nottingham University Hospitals NHS Trust.

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.

1

When a baby is born with Down's syndrome

3. Who

- It is usual practice for this to be a Consultant Paediatrician attached to the labour ward, local protocols may differ, but it is good practice for the mother's midwife or someone who has supported her during her birth to be present.

4. Preparation

- It will be necessary to gain consent from parents to undertake a blood test to look at the baby's chromosomes and give a conclusive diagnosis of Down's syndrome. During this time (when it isn't possible to be 100% sure the baby has Down's syndrome), parents overwhelmingly say they value honesty. You should say that it is suspected that the baby has Down's syndrome, but you can't be completely sure without carrying out a blood test. Be available and willing to answer queries during this time.
- Read though this list before talking to the parents.
- Read up to date information about Down's syndrome.
- Talk over what you are going to say with a colleague.

5. Gather information

- Have the DSA resource 'Congratulations on the birth of your baby' ready to give to the parents (not a photocopy). This can be downloaded here: downs-syndrome.org.uk/CongratulationsBirthBaby/
- Have the DSA's contact details to hand and, where available, information about local support groups (local contacts available from the DSA).

Down's Syndrome Association

Congratulations on the birth of your baby

A Leaflet for New Parents

A Down's Syndrome Association Publication

6. The environment

- A private room, without a desk between you and the parents.
- Ensure that there will be no phone calls or interruptions.
- Allow plenty of time — don't rush.
- Give the parents time to absorb the information and ask open questions.

7. Telling the parents

- Congratulate parents, relatives and friends on the baby's birth.
- Tell parents as soon as possible and ensure that the baby is present (if not in SCBU).
- Tell both parents together. If the partner cannot be present, ensure support for mum through a family member or friend.
- Interact with the baby and call him or her by their name.
- Consider any language barriers and have an interpreter present if necessary.
- Check that the parents have understood what you have told them.
- Arrange a follow up chat within 24 hours. Make regular checks with parents and baby. Offer a follow up call/chat after they have left hospital.

8. Language and terminology

- Be aware of body language and non-verbal cues.
- Person first terminology – your baby has Down's syndrome.
- Provide a balanced view of life for people with Down's syndrome today.
- Do not recite a list of all the possible health problems, give information about any health related screening tests that will be done in the first few weeks.
- Do not attempt to predict the future!
- Do not give a list of anything that the child will or won't achieve - you wouldn't do this for any other child.

9. Support in hospital

- Offer a choice of a private room or a bed on the ward and check in case the parents change their mind.
- Enable partner to stay overnight.
- Regularly visit mum and interact with the baby.
- Offer additional support to breast feed if required.
- Tell the parents about what will happen next.
- Inform the family's GP, Health Visitor and Community Midwife.

10. Leaving hospital

- Ensure that parents have contact information for the Down's Syndrome Association and the local support group where there is one.
- Provide the Down's syndrome weight and growth chart inserts for their baby's personal child health record (red book).
- Finally…**encourage parents to enjoy the baby days and not to be thinking too far ahead.**

Information and Support

Call the DSA Helpline
Call **0333 1212 300** or email info@downs-syndrome.org.uk for information, advice and support on any matter. The DSA can refer to medical advisors on matters relating to a baby's health.

Expectant parents
Looking Forward To Your Baby (pdf):
downs-syndrome.org.uk/LookingForwardToYourBaby/

Maternity healthcare
Management of Pregnancy when Down's syndrome has been diagnosed:
downs-syndrome.org.uk/ManagementOfPregnancy/

New parents pack
Contact the helpline for hard copies
downs-syndrome.org.uk/NewParentsPack/

- Congratulations on the birth of your baby
- Leaflet for Family and Friends
- Membership application form to join the DSA
- Benefits for Babies
- Who we are. What we do. Why we need you

Join the DSA
New parents get free membership for their child's first year:
downs-syndrome.org.uk/Membership/

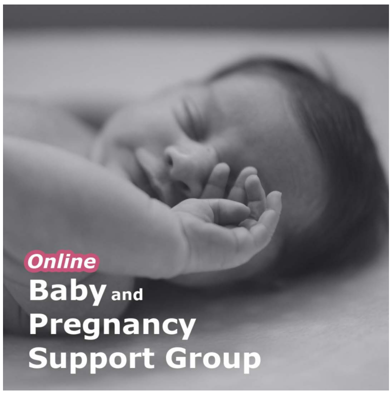
DSA health information
Find publications (produced in conjunction with the Down Syndrome Medical Interest Group of UK & Ireland) and information on health & well-being:
downs-syndrome.org.uk/about-downs-syndrome/health-and-wellbeing/

Local affiliated support groups:
downs-syndrome.org.uk/LocalSupportGroups/

Tell it Right® campaign:
downs-syndrome.org.uk/TellItRight/

Online support groups from the DSA
DSA Parent and Practitioner Group - Birth to 11 years
facebook.com/groups/DSABirthto11/

Online baby & pregnancy support group
Meet our team and ask questions on any topic, including development, communication and benefits.
downs-syndrome.org.uk/baby-and-pregnancy-support/



DSA Tell it Right® group
facebook.com/groups/DSATellItRight/

FREE Training for maternity healthcare practitioners:
Tell it Right® Midwives accredited study day.
Email training@downs-syndrome.org.uk for more information.

For more information about the resources mentioned here and how to order them, contact the Down's Syndrome Association on 0333 1212 300 email: info@downs-syndrome.org.uk