

RECOMMENDATIONS

for telling parents that their baby
has Down's syndrome



Guidelines and recommendations for medical
staff when breaking the news to parents

Who should BREAK THE NEWS?



The number of people who are able to break the news should be increased. This will ensure that there is always a professional available to talk to the parents and avoid a delay, during which time the parents will believe that everything is fine.

“The paediatrician on the labour ward was very positive – yes your baby has Down’s syndrome, but these babies respond very well to stimulation and give a great deal back.”

Determine within your hospital/department whether senior midwives should be able to share their concerns with the parents, rather than having to wait hours for a consultant.

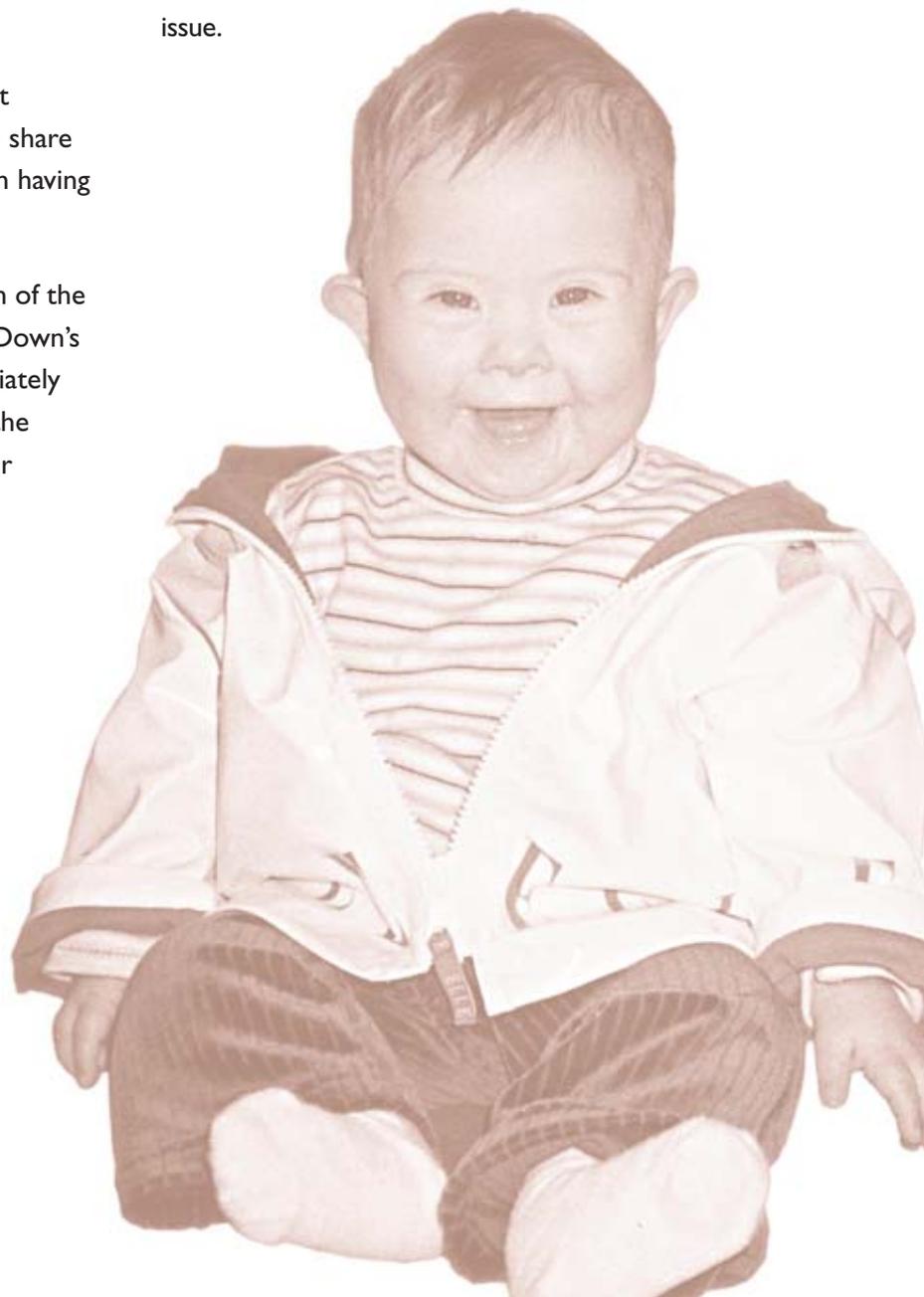
If, following the midwife’s initial examination of the baby, there is significant reason to suspect Down’s syndrome, but a paediatrician is not immediately available, after discussing her findings with the senior midwife, they should both share their concerns with the parents.

This will be particularly fitting in cases where the midwife has built a good relationship with the parents. It is important to clarify that concerns are about the baby having Down’s

syndrome, as this will prevent the parents from assuming that the situation is much worse.

Sharing these initial concerns will give the parents an opportunity to discuss any concerns that they themselves might be having about the baby. Don’t assume that the parents are unaware that there could be a problem.

This will also prevent the parent’s later realisation that staff were aware of the possibility of Down’s syndrome but had avoided the issue.



PLANNING



The Scottish Down's Syndrome Association recognise that breaking difficult news can be very distressing. It is important that you take the opportunity to plan what you are going to say with a colleague, but not the entire staff team, before approaching the parents.

Prepare in advance what information will be given to the family. This may mean doing some research beforehand. Remember that many medical journals contain outdated details and use inappropriate language. Up to date terminology is important. You can contact SDSA for advice before talking to parents – we have a 24 hour helpline on 0131 313 4225.

“I was flooded with medical facts, like he might be a dwarf. One nurse said better luck next time... I didn't want anyone feeling sorry for me”

Whenever possible, break the news when both parents are together. If this is not possible, ensure that a family member or friend is present for support. Alternatively a staff member that mum has developed a good relationship with.

Whenever possible, ensure that the baby is with the parents, when you pass on the news.

“We were given leaflets for the parents and family of a child with Down's syndrome... The nurse kissed me on the cheek... 3 days later when I broke down the tea lady came in and was most positive... the staff were all wonderful”

If it is unavoidable that the parents are told separately, consider where mum's support is coming from. Arrange to tell dad as soon as possible.

“I was told that my baby had Down's syndrome on my own. I then had to use the ward payphone to tell my husband”

If mum is a single parent, with no obvious family support, ensure that a staff member of her choosing is available to provide support and comfort for as long as is necessary. This could be anyone that mum spent time with during pregnancy or labour.

If one of the parents first language is not English, ensure that a translator is available, if not immediately, then as soon as possible. Where possible provide information material in the parent's first language.



Telling the PARENTS



Ensure that there are not too many people present when the news is given – the professional giving the news plus another member of staff, usually a nurse or midwife. This staff member should be available to talk to the

parents again at a later stage. Unknown staff, medical students and other doctors should not be present.

“The consultant we saw initially was very positive, he pointed out that children with Down’s syndrome are as individual as other children, that they respond to love and thrive as part of a family.”

Allow plenty of time. Ensure that there are no interruptions such as pagers, or telephone calls. Don’t rush.

When breaking the news, use the baby’s name whenever you refer to him/her.

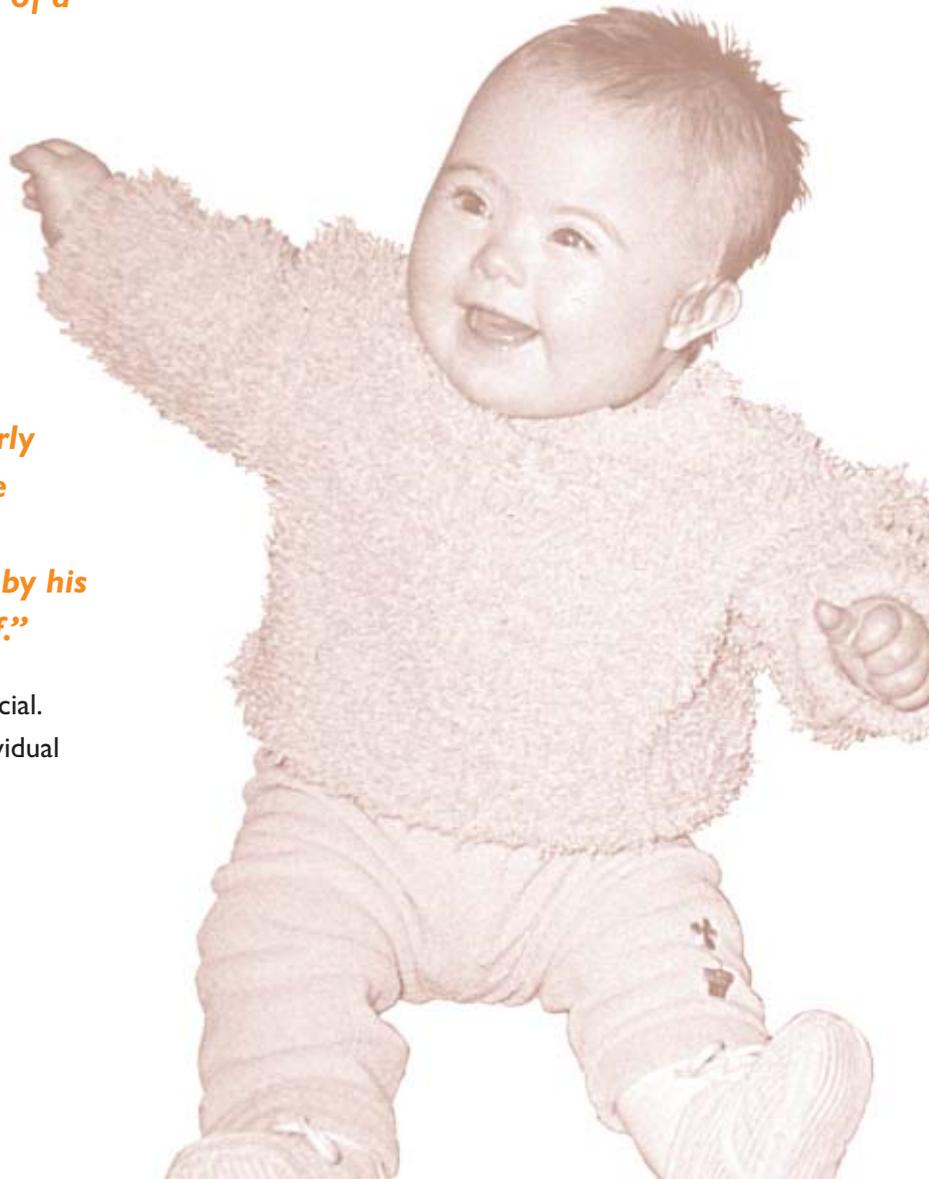
“One paediatrician was particularly negative... made us feel it was the worst tragedy that could have happened... she never called him by his name... we felt he was written off.”

The language and terminology used are crucial. Always be respectful of the child as an individual personality.

Be as realistic about the wide range of possibilities for children with Down’s syndrome, as you can. Make yourself aware of the quality of life now enjoyed by people with Down’s syndrome.

Do not present the child as a list of possible medical problems.

“The next day the paediatrician came into the room and delivered her Down’s syndrome speech – a list of everything wrong with him and that could go wrong in his entire life – leukaemia etc etc... her tone was very negative and we were devastated”



Telling the PARENTS



Allow time for the parents to ask questions. Be honest with the parents when you are sharing information, but do not try to answer questions that you do not have the answers to.

Check that the parents have understood what you have told them and ask if they have any immediate questions.

Give the parents a copy of the SDSA 'new parent' pack.

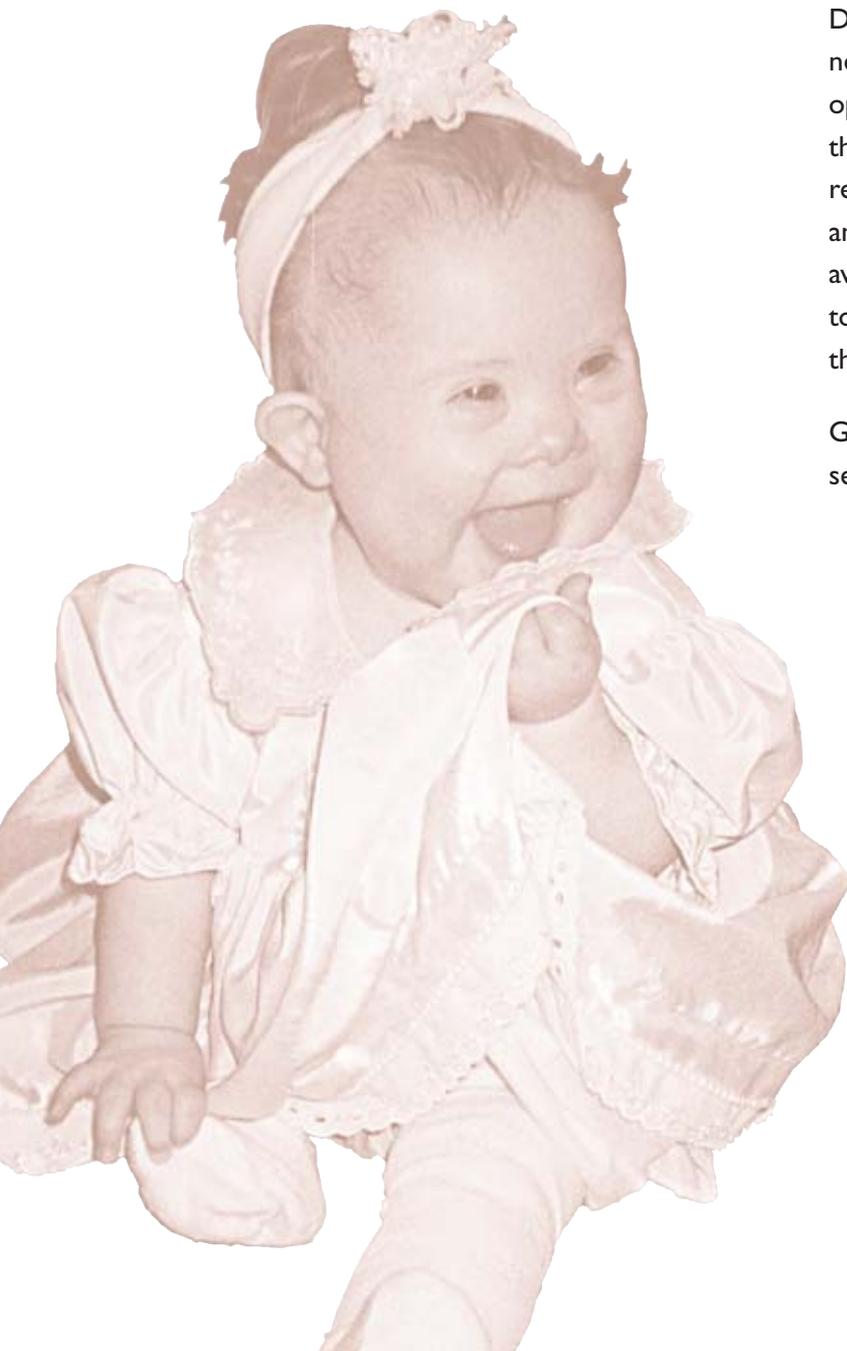
As dad will usually be the one who informs family and friends, ensure that he has access to a private room with a telephone.

Arrange a follow-up appointment in a couple of days with the parents and encourage them to write down any thoughts or questions that occur to them in the meantime.

Do not separate mum and baby from the other new mums as a matter of course. Offer mum the opportunity of having a single room, if she takes this up, ensure that people call in to see her at regular intervals. Dad may wish to stay with mum and baby overnight – this option should be made available. As time goes on, mum may wish to return to a larger ward and she should be made aware that she has this choice.

Give the family information about other support services and organisations that are available outside hospital, with details of how to contact them.

Notify the family's G.P. and community midwife – give details of the meeting with the parents and any other relevant health information.



Please REMEMBER



Parents tell us that they never forget *'how they were told, when they were told and who they were told by'*. The experience

stays with them throughout their lives and the person who goes that extra mile for them will always be remembered.

“The consultant did not bombard us with too much information straight away... They gave us and the baby time alone to let the shock sink in.”

The person who breaks the news, having prepared in advance with positive information about Down's syndrome and the support available, will be appreciated.

A named person needs to take responsibility for ensuring that the hospital always carries up to date information about Down's syndrome. SDSA hospital packs carry all the detail that parents need initially and each department should nominate a person to maintain stocks.

SDSA also has local new-parent contacts. These are parents of a child with Down's syndrome who are willing to visit new parents, either in the hospital or the home to offer support.

Encourage the parents to enjoy the 'baby days', lots of parents later regret this lost time.

People with Down's syndrome are leading full and worthwhile lives, they are all unique with individual talents and personalities.

A baby with Down's syndrome is a baby first and foremost whose birth should be celebrated.



SCOTTISH

Down's Syndrome

ASSOCIATION

helping people realise their potential

158/160 Balgreen Road, Edinburgh EH11 3AU
Tel 0131 313 4225 Fax 0131 313 4285
E-mail info@sdsa.org.uk
Internet www.sdsa.org.uk

The SDSA provides support, advice and information to people with Down's syndrome and their families/carers, professionals and the general public in Scotland.

It also seeks to raise awareness and understanding of the potential of people of all ages with Down's syndrome.

Written and published by the
Scottish Down's Syndrome Association

This edition printed 2001

SDSA would like to thank Helen Nisbet, Jean Duncan, Fiona Macintyre, Isabel Barclay, Carol Mack, Sandra Henderson, Elizabeth McNeil, Kate Sloan, Elizabeth Mackenzie, Janette Campbell, Marion Donald, Michelle Lochrie, Morag Doak.

Our models are Rachel, Lee, Josh and Lauren.

SCOTTISH CHARITY NO. SC011012