

GUIDELINES

FOR BREAKING THE NEWS TO PARENTS



جمعية صوت متلازمة داون
Saut: The Voice of Down Syndrome Society

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Introduction

Having a baby is probably the most creative thing we do. It gives us an acute sense of hope and accomplishment, a feeling of deep love, joy and pride. But these feelings are challenged when our baby is born disabled. What do parents feel then? How do they cope? Attitudes can change instantly and radically and relationships can be put at risk. How people are told can significantly influence their emotions, their beliefs, how they deal with the future, and their attitude - both to-ward their own baby and toward medical staff in general.

One in 40 babies is born impaired. When that happens, how should hospital staff react? What should they say? Years later, parents will remember exactly how the news-breaker handled the situation. Nevertheless, few health facilities seem to provide any guidance whatsoever for those who are handed the task. Jupp identified the following guidelines as PRACTICAL GUIDELINES and NOT rigid rules to help news-breakers break the news to parents.

Who should tell the parents

The news-breaker should be the PEDIATRICIAN. However, having a midwife present at the time together with a backup team of other professionals (social worker, counselor) is helpful for future support.

When to tell the parents

1. As soon as possible - normally within 24 hours of the birth if possible, or one to three days, but certainly no longer.
2. If not possible to diagnose accurately in the initial few days, then parents need to be told of your suspicions rather than be “fobbed off” with false reassurances.
 - When you are not sure: If you are in the process of carrying out tests to confirm a diagnosis, then tell parents what these tests are while you are doing them and how long it will be before the results are known
 - Be open frank and honest about the situation

Where to tell the parents?

1. Parents prefer to be told together to derive support from one another.
2. Parents should be afforded privacy and be allowed time together after the news has been broken, without fear of interruption.
3. The baby should be present during and after the time of telling. Hold the baby in your arms for a short period and then hand him or her to the parents.
4. Have a midwife and/or trained social worker present who will be on duty when you leave. They can be available when the parents need to go over the information again.

How to tell the parents?

The informant should be:

1. Known to the parents already - familiarity helps in the “NEW WORLD” to reduce anxiety.
2. Open, frank and honest - show that the parents are respected and valued by the professional.
3. Understanding and have due regard to the potential effect that the news will have upon the parents.
4. Sure of one's facts and information - parents will be setting up a new information base in which to understand their child and their child's needs.
5. Prepared to spend a lot of time with the parents.
6. Prepared to deal with the parents' emotional reactions, to respond and be sensitive to them.

What to tell the parents?

1. General points:
 - Congratulate the parents on the birth of their child
 - Present the child in a positive but realistic light
 - Convey confidence in the ability of the parents to cope with and manage their child
 - Convey warmth, insight and respect. Avoid negative predictions of the future
 - Keep the explanation simple

What to tell the parents?

2. The first interview should be a session of at least half an hour, uninterrupted. It is usually an intense emotional interchange with little transfer of actual details. Aim to cover the following areas:
 - The type of disability if known
 - The tests needed to confirm (if necessary)
 - The possible cause for the disability
 - Make parents aware that there will be further arranged meetings to discuss their child's disability in more detail
3. Further interviews need to be frequent, planned and private. They should be with the pediatrician or the midwife/social worker who was in attendance at birth. Information from previous meetings should be REPEATED, but as time goes on, expanded upon.

Other areas to cover:

1. Implications of the disability and the child's special needs.
2. Meetings with the future support agencies who will be working with the family after discharge from the hospital.
3. The importance of early intervention programs, where they are located, and how to contact them.
4. Presenting parents with packages of information.
5. A personalized information/fact sheet prepared by the news breaker, summarizing all that the parents have been told.
6. Time should be given to ensure that the parents fully understand the information provided and an out-patient appointment will need to be arranged before they leave the hospital. CONTINUITY is important as they will need to see the news-breaker in these out-patient appointments.

Some additional suggestions:

1. It is important that doctors make sure that the family understand all that is said.
2. Ensure that the family can remember the content of the information given.
3. Stress on the religious aspect to help arenas cope with the new situation.

How to help parents understand and remember the information:

1. Simplify your information:
 - Avoid using medical jargon
 - Use short words and sentences, preferably in the parents' language
 - Gear your level and style of speech to the person you are addressing
2. Categorize the information:
 - Announce and repeat the category name
 - Cover each category in detail
3. Repeat information in different ways.
4. Be specific by using concrete advice rather than general advice.
5. Tell them what they need to remember.
6. Tell them the most important things first.
7. Assume the role of a counselor.

References:

Jupp, K. (1999) Breaking the News, pp. 10-17

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