

# Down's Syndrome Screening

## The Screening Process: Information and Communication

*Element A*

## Aims and Objectives

To provide an overview of the skills necessary for effective communication during the screening process. An essential element for all health professionals involved in antenatal screening, this is an important component of the pre and post test information giving process.

# Aims and Objectives

## The session will include:

- An overview of the screening process in relation to the provision of information
- Identification of the components of information required pre and post screening
- Presentation of the skills required by professionals to facilitate effective communication and therefore promote informed choice

# Providing information during the screening process

# The First Principle of Maternity Care

The woman must be the focus of maternity care. She should feel that she is in control of what is happening to her and able to make decisions about her care, based on her needs, having discussed matters fully with the professionals involved.

*Department of Health 1993  
Changing Childbirth*

Patients have a fundamental legal and ethical right to determine what happens to their own bodies. Valid consent to treatment is therefore absolutely central in all forms of healthcare.... Seeking consent is also a matter of common courtesy between health professionals and patients.

*Department of Health HSC 2001/023*  
*Good practice in consent*

# Balancing Different Perspectives in Screening Programmes

**Professional Choice**

Clinician decides and woman agrees

**Professional as agent**

Clinician explores woman's views and clinician decides

**Shared decision-making**

Clinician and woman share information and reach mutual decision

**Consumer Choice**

Clinician informs and woman decides



**Spectrum of decision-making**

*(Emery Health Expectations 2000)*

# Information Strategy

## Process:

- Information provision
- Discussion
- Decision making

## Stages:

- Single stage process
- Two or more stage process

## Influential Factors

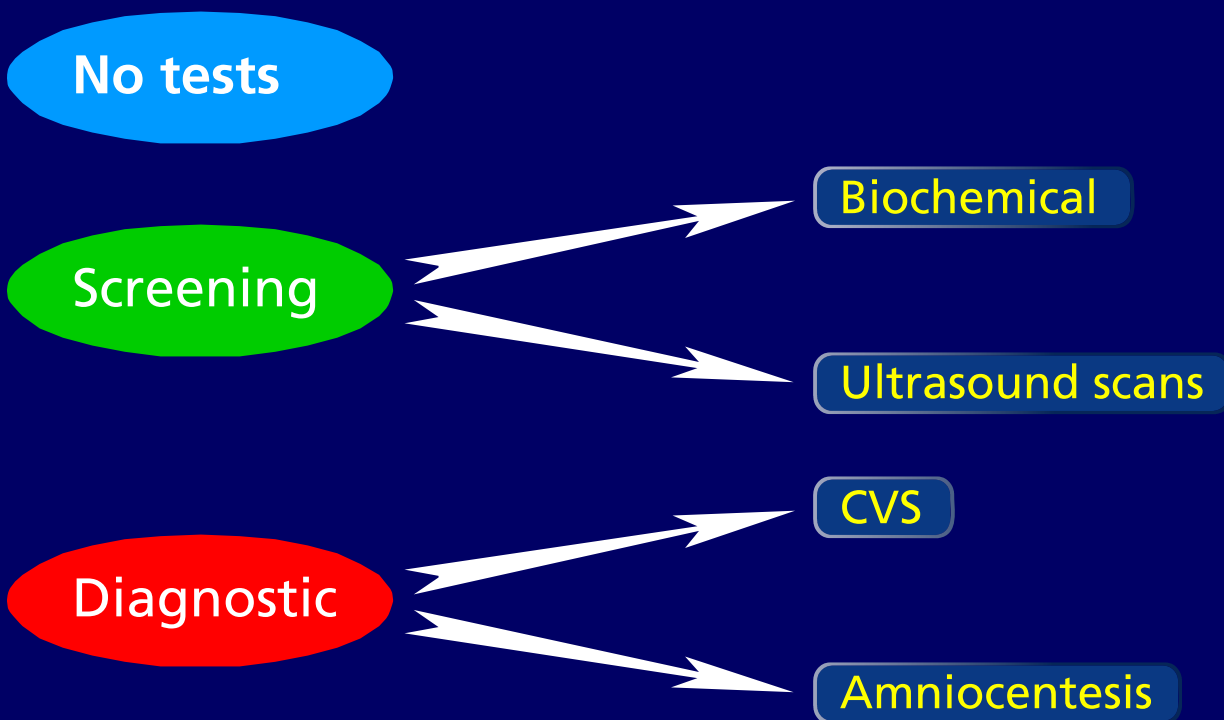
- The woman's partner
- Her family
- Religion
- Age
- Social background
- Prior knowledge
- Personal experiences and beliefs
- Presentation of the tests
- Professional bias
- Local arrangements

# The components of pre and post test screening information giving

## Pre-test Information

- Determine the level of knowledge of the condition and give information as appropriate
- Determine the level of knowledge of the screening tests and give information as appropriate

## Options available



## Pre-test Information

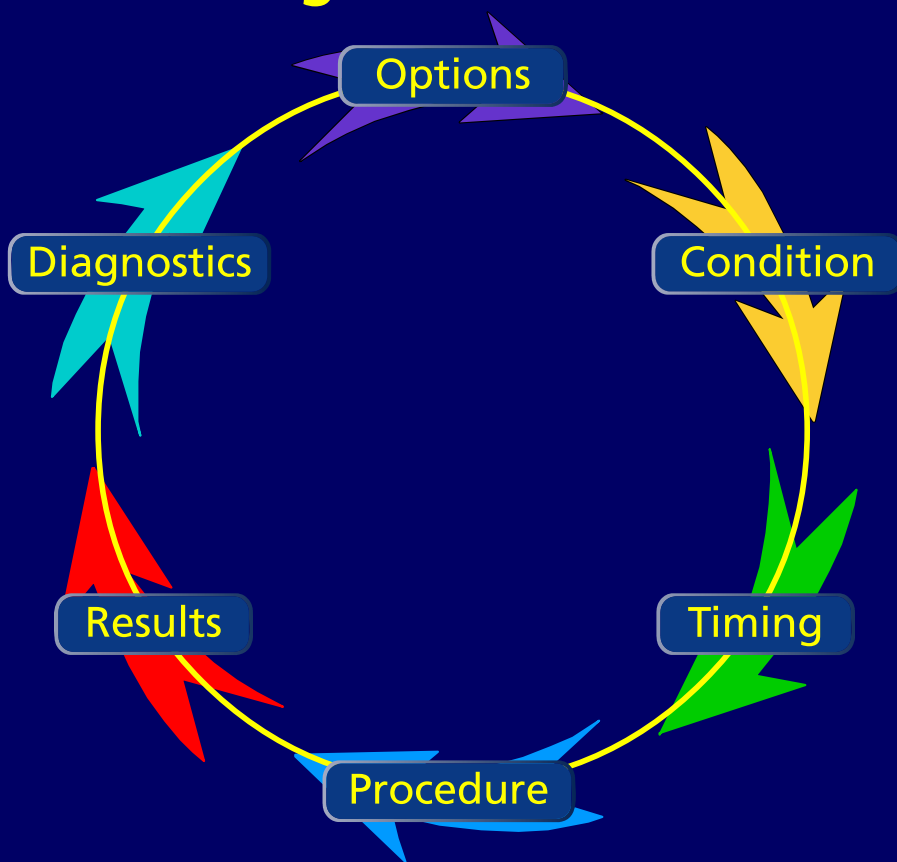
- Options available
- Conditions being screened for
- Timing of test
- How the test will be done
- Meaning of the test
- Meaning of 'high risk' result
- Meaning of 'low risk' result

## Pre-test Information

- Probability of 'high risk' result
- Options following a 'high risk' result
- Reporting of the screening result
- Options following screening result
- Options following diagnosis of fetal abnormality
- Further information / contact numbers

## Respective of local arrangements

# Information Giving



# Options Following a 'High Risk' Screening Result

- Continue the pregnancy without undergoing a diagnostic test
- **Diagnostic tests**
  - Amniocentesis
  - CVS

# Following Confirmation of a Fetal Abnormality

## Support

- Appropriate professionals - Paediatrician, Clergy
- Support agencies - Antenatal Results & Choices (ARC)  
Contact A Family (CAF)

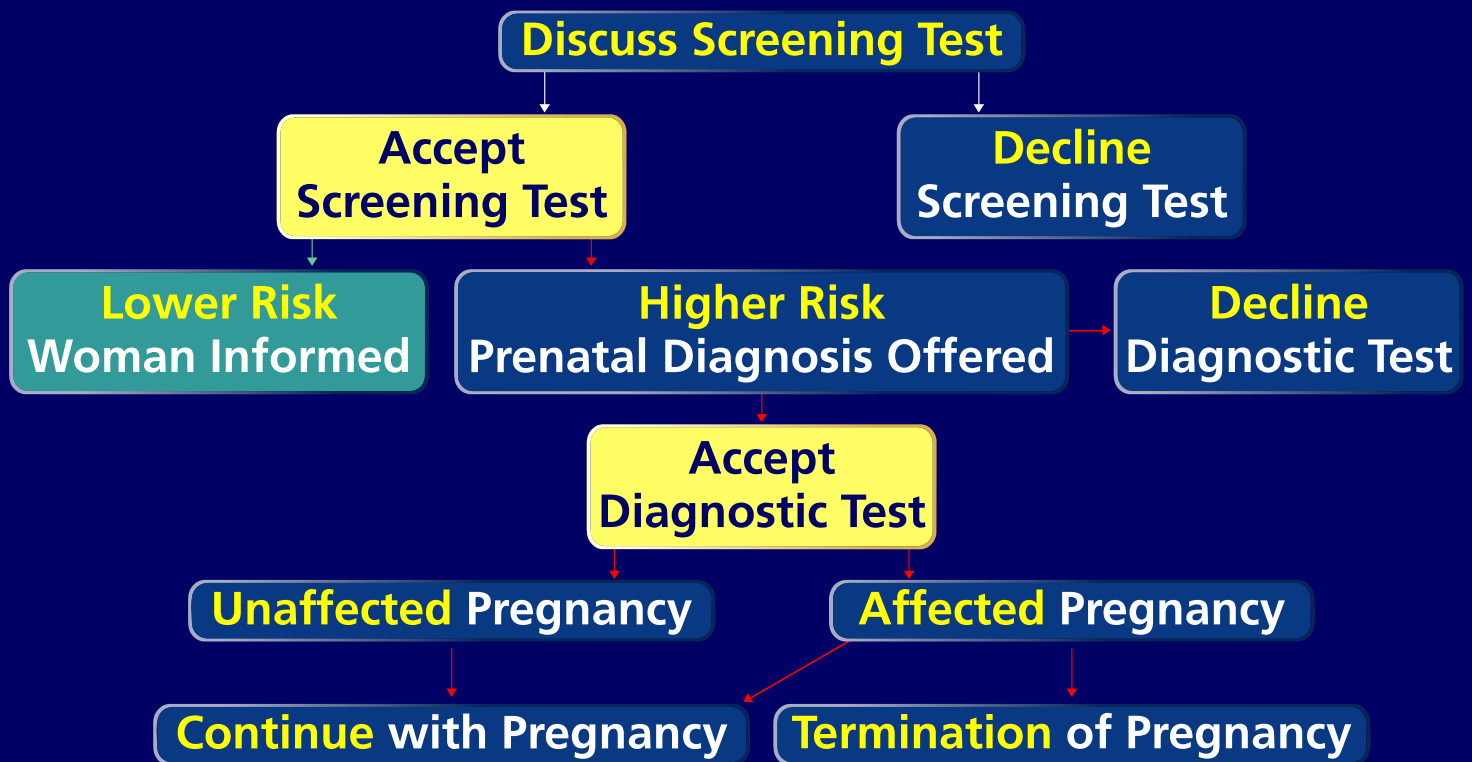
## Literature

## TIME !!!

## Planning for:-

- Continuance of pregnancy - cardiac scans, paediatric care
- Termination - place, method, after-care arrangements

# Process Flowchart



# Communication Skills for Professionals

Professionals cannot (and should not have to) depend on their personal resources in order to give good care. All professionals need to learn and practice skills - most particularly listening skills, communication and information-giving skills, and the skills to respond appropriately.

*(Kohner and Leftwich 1995)*

## Self Awareness

The starting point for learning any skills with people is to become aware of ourselves. Our own attitudes and feelings fundamentally influence the way in which we are able to be with people in times of acute distress. It is impossible to care professionally without also calling upon our personal responsibility.

*(Kohner and Leftwich 1995)*

# What do Parents Need

- Information
- Support
- Honesty and Empathy
- Confidentiality
- Time and Space

## Information

Information needs to be given in a way that helps make it clear to the parents that the health professional recognises the impact the diagnosis will have on the parents.

The diagnosis of abnormalities which are perceived by health professionals as 'less severe' than others still cause significant distress for parents.

*(Statham, Solomou & Green, 2001)*

# Information

- Effective listening
- Medical jargon
- Talking as an equal



## Support

- Be explicit that you will support **their** choices and decisions
- Leave them with a contact number for a named person
- Inform the GP/community midwife of situation
- Information on support groups

## Honesty and Empathy

- Provide them with the facts as required
- It may be appropriate to reassure them about their decision **after** it is made
- Be prepared for changes in decision
- Acknowledge it is unrealistic to expect to 'enter anothers world' on the basis of a 30 minute consultation
- 'I understand how you feel' scenario

# Confidentiality

Women trust in the professional to be their advocate. Information is often given in confidence and with the expectation that it is only used for the purpose in which it is given.

## Time and Space

- Don't rush people into decisions
- Try to go at their pace in terms of plan of care
- Consider the environment in which discussions are held
- Keep a balance between support and 'pressure'

## How Can You Help?

- Provide the elements that are needed to make decisions appropriate for them
- Support their decisions
- Know all your facts
- General care aspects

# Professional Dilemmas

- When the outcome is uncertain
- When there is a time 'constraint'
- When there is a difference of opinion or family pressure

# Sources of Pressure

## Fear of

- Causing pain
- Saying 'I don't know'
- Sympathetic pain
- Being blamed
- Eliciting a reaction
- Medico-legal issues



For parents, the quality of the care they receive is crucial. Few forget their experience of loss. Most have vivid memories of what happened, what was done and what was said, and these memories may stay with them for months, years and often a lifetime to come.

*(Brian and Fairbairn 1996)*