

# **Session 2**

## **Psychosocial Booklets**

# Unit 6.1 Patient Education

- ‘to develop informative, accurate and patient centred information about all aspects of genetic testing including scientific as well as psychological and social information. A list of other reputable sources will also be available’.
- So far we have developed 11 ‘scientific’ patient information leaflets.

**Key Finding** - Written information more likely to discuss hard factual information than qualitative experience based information.

## **Why?**

1. Acceptability and expectation of writing about psychosocial issues may vary across different cultures.
2. Clinicians may believe this to be outside their remit and the role of patient groups/ social services.

Studies have shown patients do require psychosocial information and that psychosocial outcomes are commonly experienced by patients and families. Some examples:

- Genetic testing – stressful, anxious experience (Dinc 2006)
- Carriers – feelings of guilt, blame, stigmatisation (James, 2006)

- Predictive testing breast/ovarian cancer – younger female carriers more prone to ‘worry’, but engage in significantly more risk management strategies (Watson 2004)
- Children with genetic condition (sickle cell) –ve missing more school, less athletic, +ve more prosocial, less aggressive (Noll 07)

- Effect on parents – poor family functioning (Garwick 97) worry about health of future children (Weil 02). Mothers reported better acceptance and coping with child's illness than fathers (Saviolo-Negrin 99)
- Effect on siblings – take on additional caretaking responsibilities (Van Riper 2003) enhanced personal maturation (Kramer 84)

Numerous genetic bodies highlight the need for clinicians to provide psychosocial support to patients and families:

International Society Nurses in Genetics (ISONG), role of genetic nurses is to 'provide genetic information and psychosocial support to families'.

NCHPEG: healthcare professionals should 'be able to understand social and psychological implications of genetic services'.

# Session 2 Task

- 1) To agree that psychosocial information is necessary and useful, and that because such information is currently lacking there is a need to develop it.
- 2) To make suggestions as to what information it would be useful to develop.
- 3) To prioritise these suggestions.

# Initial Thoughts.....

Most psychosocial information that has been developed relates to predictive/presymptomatic genetic tests (Huntington's, breast/ovarian cancer etc).

No general psychosocial information (non disease specific) for rarer genetic conditions.

## Possible themes:

1. Information for parents whose child has been referred to a genetic specialist (adaptation of our 'genetic appt' leaflet).
2. Information for parents whose child has been recently diagnosed with a genetic condition.
3. Information for parents who have been unable to find a diagnosis for their child.