

ISPN Statement on Antenatal Counselling – An ethical and professional framework

1 April 2025

Statement of purpose:

The purpose of antenatal counselling is to provide expert opinion on antenatally identified neurological conditions and their lifelong management, to help families prepare for their child's needs and contribute to any shared decision making through the pregnancy.

There may be multifaceted demands placed on professionals from personal, professional, and organisational beliefs and expectations which may lead to conflict. This statement aims to provide a framework to guide antenatal consultation and help resolve these conflicts.

Guiding ethical principles

Respect for autonomy

• Pregnant women should be fully informed in a value neutral collaborative manner and have the right to make decisions about their care and the care of their baby.

• Non-maleficence

- The prevention harm, both physical and mental extends to both mother, baby, and family and can be mitigated by seeking to understand the needs, values, and beliefs of the family from the outset.
- In some conditions the zone of maternal foetal conflict emerges and needs to be acknowledged. If significant, involvement of an independent clinical ethics team is recommended.

• Beneficence

- Information given is aimed to be beneficial to the family and other practitioners involved in their care.
- In the setting of proposed foetal therapy or intervention there are 3 additional criteria to satisfy beneficence
 - The therapy should be lifesaving or prevent or substantially mitigate serious or irreversible disease.
 - The therapy should be a low mortality intervention for the baby and low or manageable risk of serious disease injury or handicap to the baby.
 - The therapy should have low maternal mortality and morbidity.
- Justice
 - Services should be distributed fairly to those in need, and families should be made aware of all supports and resources.



• Veracity, Integrity, and Humility

- In addition to the duty to be truthful and provide expert information, we must also address and disclose our own expertise and limitations (including resource) and any biases arising from research interests, specific practice interests or personal convictions.
- Information should be provided to families on all the treatment / management options, including information regarding resources or other practitioners who may provide these options.

• Respect for confidentiality

- Confidentiality of consultations is paramount and a foundation of the therapeutic relationship.
- The complex care and complex social needs that may be encountered (e.g. surrogacy) necessitate involvement of other professionals (e.g. clinical ethics boards) being included with family consent.

Practical points

- The purpose of the consultation is to provide information to families. Whilst this may aid them with decision making, our role is to give information rather than direction.
- Family groups identify that avoidance of negative phrases is important. This particularly relates to emotive terminology such as lemon head or banana sign which are descriptive and helpful in a clinical context but challenging for families to hear.
- Families value accuracy in the information given, and as such clearly identifying the limits of prognostication and prediction is paramount.
- If families express a decision or value, it is important to avoid any appearance of judging that decision.
- As social and care contexts become increasingly complex it is helpful to identify all stakeholders early in the consultation.
- In the context of clinical research, trials, or new techniques involvement of a clinical or institutional ethics board is mandatory.