

This response was submitted to the consultation held by the Nuffield Council on Bioethics on Critical Care Decisions in Fetal and Neonatal Medicine: Ethical issues during March to June 2005. The views expressed are solely those of the respondent(s) and not those of the Council

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**QUESTIONS ANSWERED:**

**Question 1**

**ANSWER:**

To my opinion this can only be decided on a case by case basis. I do not think that a general rule can be given, as decision making in these cases always requires a careful weighing of all facts and circumstances, including more or less certain assumptions concerning individual prognosis. At least in theory we must assume that such a situation may occur. However, this requires justification of very strong paternalism. A basic criterium should be that the intervention is in the presumed best interests of BOTH the mother and the child, and the burden of proof and full responsibility for all foreseen and unforeseen consequences rests with the professionals who take this decision.

**Question 2**

**ANSWER:**

To my opinion, these decisions can not be made for categories of impairments but only on a case by case basis.

**Question 3**

**ANSWER:**

1) To my opinion, no pertinent statements concerning the moral status of embryo's and fetuses can be made. It can not be the task of a Working Party making policy recommendations to draw up such statements. However, a statement about the unresolvable nature of this issue could be important as a starting point for further discussion. 2) To my opinion, dealing with the question of discriminating between acting and omitting to act is of utmost importance for daily practice. In clinical decision making the relevant differences between the moral, legal and psychological aspects of acts and omissions often get mixed up. For those who must act - or refrain from acting - at the bedside the psychological implications maybe a major concern. Recognition of this by the Working Party would be very supportive for all parties involved, both professionals and parents. Moral and legal arguments cannot relieve psychological burdens. 3) The importance of questions about the quality of life should be pointed at, however, no answers with regard to contents should be given.

**Question 4**

**ANSWER:**

Quality of life for a child: this can only be a 'best guess' in each individual case, according to circumstances. And any 'best guess' can turn out to be very wrong later. Experienced professionals are very aware of this and of the heavy burden it puts on themselves and on the parents. Certainly not always, but in many cases religious and spiritual influences - both on the part of the parents and the professionals involved - will play a role in decision making. For coming to terms with the outcomes of the decisions

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made religious, spiritual, and cultural resources can be very supportive. However, I cannot see a special task for the Working Party on this point. Mass media certainly do influence decision making. However, this is more likely to be so in cases of protracted end-of-life decision making. In prenatal medicine, peri- and neonatology individual decisions usually need to be made very instantaneously. Public debate, however, may shape the climate in which decisions are being made.

#### **Question 5**

##### **ANSWER:**

To my opinion, the parents should be the primary decision makers. In case of difference of opinion between the parents, the wishes of the pregnant woman or the mother that just gave birth to the child should prevail, as I assume at least prima facie that there is a special bond between a mother and her child that justifies her role in deciding on behalf of it. Exceptions may occur in special circumstances: e.g. decisions cannot be left to a parent in psychosis or other mental crisis, or to a (temporarily or not) physically incapacitated parent. The option of using the law to challenge medical advice should always be available.

#### **Question 6**

##### **ANSWER:**

For broad policy making this may be an issue. In individual cases such considerations may not be absent, however, to my opinion they should never be decisive. A dilemma may occur when decisions concerning the allocation of resources at the bedside need to be made.

#### **Question 7**

##### **ANSWER:**

This is beyond my field of expertise.

#### **Question 8**

##### **ANSWER:**

To my opinion, carefully considered directive professional guidance can be very helpful, as long as it leaves enough space for individual case-adjusted decision making. Setting a minimum age for resuscitation: I cannot judge this from my professional expertise. Neither for the UK nor for my own country.

#### **Question 9**

##### **ANSWER:**

I cannot judge this for the UK. However, professional guidelines might be a more flexible instrument, and more helpful because directly oriented towards clinical practice.