

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.

## **NATIONAL COUNCIL OW WOMEN OF GREAT BRITAIN**

### **Question 1.**

In such a case, it is difficult to see any measure that would be appropriate to sustain life if there was no prospect of correction or a cure. If a correction or cure is possible then the risks to the child and the mother and the probability of a successful outcome must influence whether any action 'to prolong life' is advisable. Low risks and high probability of success are essential

The best solution will be arrived at by open discussion with all parties – including grandparents – and hopefully a consensus will be reached. Views expressed by members varied from 'the mother's view must never be overridden, the foetus is basically her body' to 'one can envisage a situation where a mother may not be able to understand fully the implications'. Taking action to sustain life against her wishes would always be unacceptable. The development of the technology has placed a burden of decision on parents, particularly the mother, who will be in a distressed and emotional state and it may be in the best interest of all concerned that the wishes of the mother to sustain life be overruled. In the long term it may be a relief to the mother that the decision was taken out of her hands.

### **Question 2.**

The responsibility of the medical team is heavy and despite having the skills to 'help', the decision not to use them must always be considered as an option.

The decision of what to do or not to do is not only dependent on the particular problem – e.g. 'congenital abnormalities' - but also the severity of the problem and the chance of overcoming it/them. There will be cases under all these headings when 'no prolonging of life' is the kindest and most ethical decision. What is extremely premature'?

### **Question 3.**

These are interesting and important questions for discussion but there were queries as to their relevancy to 'prolonging life' of foetuses and the newborn with severe health problems:-

- a) In 1. The group considered the term 'moral status' needed clarification. It was also felt that this was more relevant to a healthy foetus than one whose life needed 'sustaining'. Prolonging the life of a foetus was considered to be a medical and family problem.
- b) In 2. The legality of acting or omitting to act must also be considered. Doctors must not be pressurised into 'acting' in case of legal repercussions rather than 'not acting' which would be kinder and 'more ethical' for the child and family. The law must enable the agreed right/ethical solution for each case to be followed,
- c) In 3. The quality of life must cover all the parties involved. Statistics regarding the break up of families and facts regarding the affect on siblings, marriages etc should be available.

### **Question 4.**

All these questions are relevant. It is hoped that evidence will be taken from parents and families as well as individuals that have faced this issue – both successful and unsuccessful cases. The members of the Working Party although well versed in discussion of ethical matters may not have had any personal experience: theory and knowledge of ethical matters are no substitutes for practical experience.

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.

The Working Group should not be the only ones to consider these questions. Had these questions been asked in the consultation, responses may well have provided valuable and informative contributions towards finding the answers. One NCW member defined the quality of life as 'the ability to live with dignity, have reasonable independence and relate to family and friends'. Religious and spiritual influences will affect decisions and for each case they will be different influences. Media influences public opinion but should not intrude on particular case decisions.

### **Question 5.**

Every case will be different – a case by case approach should be employed.

Generalising, parents are best placed to judge the quality of life of a child as they will have to cope. The parents, especially the mother, should have most say but only after detailed and sympathetic medical advice. Discussion with someone who has had personal experience may be helpful. ['When parents are involved' implies this is not always the case. Surely they are always involved.]

Sadly, agreement is not always reached. It is difficult to see how the law is able to judge the situation for the child, the parents and the family and equally difficult to see how access to the law could be denied.

### **Question 6.**

The majority of members in the discussion group agreed that private and State economic considerations must be part of the decision. The 200% increase of neo-natal consultants in a particular London hospital in recent years was quoted. Resources are limited. A very small minority of members felt economics should not be involved.

### **Question 7.**

[There appears to be two errors in this question a) the omission of 'year' after 'life' and b) the omission of 'n' at the end of 'give'.]

These situations are not the same. A middle aged or elderly person is probably progressing from a state of independence to one of dependence over a limited period of time. A newborn child must be supported until independence is achieved and with possible disability this could be lifelong.

### **Question 8.**

The quality and quantity of professional guidance was questioned. It could help decision-making but parents must not feel pressurised. Evidence from other countries suggests setting a minimum age should be considered.

### **Question 9.**

The setting of guidelines can be constructive and supportive, however, the pace at which legal controls are put in place may be outpaced by the technology. As each case will be different further legislation was not supported.