

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.

**Ms Marilyn Mason**

**Question 1**

**ANSWER:**

For humanists, that is non-religious people who base their moral values on reason, experience and empathy, the main issue in these cases is likely to be the prevention or alleviation of suffering -and that should be the overriding principle and motivation of any measures taken. Pregnant women and parents do not have the right to cause suffering through neglect or deliberate harm, or to prolong the suffering of their child, born or unborn, unless some good can come out of it (e.g. a series of painful interventions that leads to a better quality of life could be justified; a series of interventions that ends in an all too predictable death cannot be). So we can envisage circumstances where to protect a fetus or child from suffering, it would be appropriate to override the wishes of a pregnant woman. A distinction should be made between pain / suffering and disability, as it should be possible, if there is parental support, to ensure a reasonable quality of life for a disabled child.

**Question 2**

**ANSWER:**

If the baby is likely to live only a short and painful life (and we acknowledge the difficulties of assessment and prediction) most humanists would think it unnecessary and cruel to prolong life. In the case of disability or abnormality, much will depend on the parents' willingness and ability to care for the child. If they make a fully informed choice to prolong a life that has a good chance of being viable, then their wishes should be respected. However, the outlook for a disabled or abnormal child is poor in the absence of parental love and support, and this might be another reason not to intervene to prolong life.

**Question 3**

**ANSWER:**

Yes, these are the questions that should be considered. In order of importance, we would put 2 first (as too much pain and suffering both at the beginning and at the end of life has been caused by this dubious distinction); then 1; then 3, which is always going to be a difficult one to resolve as it is so subjective - though it would be worth considering / resolving who is to decide questions about quality of life.

**Question 4**

**ANSWER:**

Yes, these are the questions should be considered. An additional question to be considered is about the amount of support society is prepared to offer the disabled and their carers.

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**Question 5**

**ANSWER:**

The first question is both crucial and difficult. On balance, medical staff are best placed to judge the physical aspects of quality of life - the likely pain, the level of disability, the probable length of life etc. Parents, on the other hand, must surely be the best judges of their ability to care for the child, and may, if they are very close to the child, be the best judges of its emotions and state of mind. We do not know how conflicting views should be resolved, or who should take precedence. There may be cases where using the law clarifies the issues and the law. Ensuring that everyone concerned is heard, and is seen to be doing their best for the child, may lead to some kind of resolution, whatever the decision - but there must be less cumbersome and stressful ways of doing this than going to court.

**Question 6**

**ANSWER:**

We don't know.

**Question 7**

**ANSWER:**

We don't know.

**Question 8**

**ANSWER:**

Yes, probably. Yes, probably.

**Question 9**

**ANSWER:**

Guidance may be more useful than new legislation. Existing laws, including human rights law, seem to cover most situations.