

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

Sub-group of North Nottinghamshire Local Research Ethics Committee

Answers to the questions

1. a) If reasonable to parents and their doctor, but who controls this, and who defines abnormalities?
b) No. The mother's consent must be obtained (or the consent of her guardian if she is unable to consent).
2. There is never an absolute contradiction to treatment to prolong life, but in the 4th example treatment is usually withheld or withdrawn.
3. These seem to be the principal ethical questions. However the aim should be to develop guidelines to limit prioritized suffering, rather than trying to decide what is right or wrong.
4. It may be more practical to consider the nature and degree of prioritized suffering in the child or family, rather than the quality of life of the child. For some people the value of life and the importance of the individual however disabled will be paramount. For many the whole process of decision making will involve coming to terms with conflicting emotion. The availability of emotional and spiritual support for example from hospital chaplaincy or other qualified health professionals is vital to enable clear communication and to facilitate an agreed course of action.
5. These questions are partly answered in the discussions about basic ethical values and their consequences in the introduction. Normally parents and their doctor agree a plan. However, parental understanding is critical and problematic. Other people can be involved within the codes of professional conduct and confidentiality. Legal help is rarely needed or desirable. A guideline aimed at minimising prioritized suffering may help resolve differences.
6. Resources do affect these decisions, but are likely to be of minor importance in most cases.
7. They are probably equivalent, but expected length of life may be more important.
8. Guidelines would be useful, but should not be too restrictive or directive. Parents and their doctor should come to their own decisions.
9. New legislation is unlikely to be helpful.