

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

ANON 3

QUESTIONS ANSWERED:

Question 1

ANSWER:

The pregnant woman's wishes should be paramount.

Question 2

ANSWER:

I offer my opinions as the mother of a baby who suffered severe birth asphyxia and whose prognosis was very poor. He made a complete recovery as far as we can tell, and is now a normal, healthy boy who is doing well at school. I have heard other similar stories of children whose outcome exceeded expectations. It is reasonable to ask medical professionals for their opinion on the basis of their experience, and for parents to use those opinions. It remains an opinion, however, and should not be regarded as a prediction since each individual case is different. An important point is that not one of the medical staff involved in my son's care have seen him since he left hospital as a baby and they are not aware of his progress. Since they do not see the more positive outcomes, the experience of medical professionals is, perhaps, based upon the worst cases. We can only guess at social, technological or medical developments which may improve the future quality of life of any baby born today. For example, the average life expectancy for a child born with Cystic Fibrosis has risen from 5 years to over 30 years since the 1960's. Any prediction of life expectancy can only be based upon current figures. There have been advances in the facilities and support available for people with disabilities. The days of having to let babies die because society cannot cope with abnormalities are long gone.

Question 3

ANSWER:

These decisions should be made by the parents.

Question 5

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ANSWER:

Quality of life predictions may be an interesting subject for academic discourse, but it is the parents who live with the child, dry their tears and change the bed-sheets. I will be always be my son's mother and he will always be my son and whatever happens to him, I have to live with for the remainder of my life. Medical and legal professionals, on the other hand, move on. It is not their place to make such decisions. Parents who find such decisions too difficult to bear can resort, if they wish, to following professional advice, but the wishes of the parents (and mother should take priority over father, if necessary, since the mother bears the child), should be paramount.

Question 6

ANSWER:

Economics should not be a factor. Babies shouldn't be allowed to die because they might cost a lot of money to look after. There has been a lack of research into miscarriage, premature birth and stillbirth in the past, perhaps because there has been no economic imperative. Improvements in understanding and preventing premature births would be a better approach to dealing with the economic burden imposed by the survival of babies that would previously had died.