

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  
Miss Mari Owen

## **QUESTIONS ANSWERED:**

### **Question 6**

#### **ANSWER:**

as little as possible. I understand that neonatal care is an expensive business but as a civilized society we have a responsibility to protect and care for the weakest in our society. as a parent who has been through the nnu experience I witnessed first hand how money subtly influenced every aspect of my daughters care, there were times when i was concerned that the financial affairs of the nhs trust had a direct influence over the standard of care my baby received, I would be concerned that different trusts can set budgets for nnu units depending on their perceived importance of nn services, budget constraints must at times play on the minds of medics when making decisions to carry on with treatment or whether to resuscitate at all, some faceless suit should not influence these life and death decisions, we need to give all babies born in this country an equal chance. Trusts need to be forced to fund nn services adequately and fairly.

### **Question 8**

#### **ANSWER:**

in my opinion guidelines are helpful for medical staff in this grey area, what would be the rights of a parent if medics didn't resuscitate when the parents felt they should, fear of action shouldn't push medics into resuscitating when their clinical judgment would say otherwise, there does need however need to be a consensus nationwide it would be a terrible cruelty for one baby in one part of the country to have a chance at life when another elsewhere wouldn't. a minimum limit would help parents know what to expect but is trying to put a box around something which is unique, dates of pregnancy are not always accurate, limiting factors in the womb are different and the constitution of each fetus is different 24 weeks means nothing . as difficult as it can be we must allow doctors to make impartial decisions at birth. Experienced pediatrics have an idea at birth of outcomes. i find the idea of asking parents their view at this stage awful. We are dealing with women at their most vulnerable, you cant ask someone to take a decision on the life or death of their own baby, still inside them when they are in the throwes of premature labour. There is no rational decision to be made by a parent then, also their exposure to different media sources may give them completely different expectations for the prognosis for their child. i understand that epicure study paints a bleak picture for the extremely preterm but epicure is surely long long out of date, a decade in neonatal care is massive, I acknowledge that we do not truly know the prognosis for pre 24 week babies born today but we have surely made substantial improvements, and if not then why not? i really think that there is a danger that by setting dates and deadlines in stone you can end up in very few years with them far out of touch, the deadline for abortion is a example. surely in the gray area between 22 and 24 weeks we need to make case by case assessments and avoid the suffering that deadlines cause, this is an issue particularly close to my heart as i had my daughter at 23+6 can 24 hours really mean the difference between life and death for a baby?