

**Nuffield Council on Bioethics**  
**Consultation on prolonging life in fetuses and the newborn, June 2005**

**BHA response**

**Question 1**

**In cases where a fetus may suffer from serious abnormalities that are likely to be disabling in the long term, what measures may it be appropriate to take to sustain the life of the fetus or, where possible, to correct those abnormalities before birth?**

**Do you consider that there are ever circumstances when it would be appropriate to override the wishes of the pregnant woman? <sup>10</sup>**

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**

**In which of these circumstances, if any, should medicine and surgery not be used to prolong the life of the newborn?**

- **When the baby is extremely premature**
- **When the baby has congenital abnormalities**
- **When the baby has poor prospects for survival because of a genetic or other disorder, or because of growth restriction during the pregnancy**
- **When the baby has acquired brain damage and is considered to be likely to have severe disabilities later in life**

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.

**In your view, are these the principal ethical questions that the Working Party should consider?**

- 1. The moral status of the fetus**
- 2. Acting and omitting to act**

### **3. Questions about the quality of life**

#### **Which of these or other ethical questions would you identify as the most important?**

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.

#### **The Working Party has identified the following questions for discussion:**

- **What might we mean by 'quality of life' for a child?**
- **How do religious and spiritual influences affect decisions?**
- **How do the mass media influence decisions?**

**In your view, are these questions that the Working Party should consider? Should any of these questions be omitted, or are there additional questions that should be included? Which social questions would you identify as the most important?**

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.

#### **Who is best placed to judge the quality of life for a child?**

**When families as well as professionals are involved, whose decision should carry the most weight on whether or not to intervene to prolong the life of a fetus or a newborn baby?**

**Examples of people likely to be involved: the mother, the father, other family members, doctors or other healthcare professionals, healthcare managers, the courts, the social services.**

**When parents are involved, whose views should take precedence? For example: mother, father, parents together.**

**Who else should be involved?**

**How should such decisions be made, and how should any differences in view between the parties involved be resolved?**

**When, if at all, do you think that people should use the law to challenge medical advice?**

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.

**How much weight (if any) should be given to economic considerations in determining whether to prolong the life of fetuses or the newborn? Would drawing up more directive professional guidance be helpful to parents and professionals?**

We don't know.

**Should a quality-adjusted life (QALY) (or another measure of health gain) for a newborn child be give the same weight as a QALY for a middle aged or elderly person?**

We don't know.

**If so, should the UK follow practice in other countries and set a minimum age below which resuscitation normally would not be permitted?**

Yes, probably.

Yes, probably.

**Would drawing up new legislation in this area be helpful to parents and professionals?**

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