

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

Revd Canon Dr Maureen F. Palmer

## **QUESTIONS ANSWERED:**

### **Question 1**

#### **ANSWER:**

I believe that many factors here should be taken into account. Although I believe in 'sanctity of life' and that there can never be justification for 'killing' a foetus, there are circumstances where death is not the worst thing that can happen. Sustaining the life of a child born extremely prematurely may not be in the child's best interest, nor in the interest of the family, nor indeed in the interest of the community. A child who has to be in intensive care for a long period is deprived of the contact between mother and baby, and I think there is sufficient research now to suggest that this is detrimental to the child's future. In addition, keeping a child in intensive care for long periods may prevent a child with more prospects from receiving the treatment that he/she needs. I think there may be circumstances when the wishes of the pregnant woman should be overridden, especially if there is danger of self-harm or harm to the neonate.

### **Question 2**

#### **ANSWER:**

I do not believe that medicine or surgery should be used in any of these cases at present. To subject parents and the child to painful surgery with little hope of improvement in quality of life for the child would seem to me ethically unsound. [Pastorally, I have had contact with a family where a neonate had five operations over a period of sixteen days to correct congenital defects, each operation raised hopes for survival and correction, but each time the hopes were dashed and the child died aged 16 days. The parents subsequently said they wished that they had not consented to heroic surgery. We may improve techniques sufficiently for such intervention to occur at some future time.

### **Question 3**

#### **ANSWER:**

These are the questions that the Working Party should consider. They are all equally important.

### **Question 5**

#### **ANSWER:**

Decisions concerning treatment of the child must be taken by the parents and the doctors together. Grandparents may also be involved but they should not be the major decision makers. Where there is conflict between the parents and doctors, perhaps there could be an independent mediation panel who would listen to both parties and try to help to resolve the situation. I believe involvement of the law should be a last resort strategy.

### **Question 4**

#### **ANSWER:**

Quality of life means a life of relative freedom from physical pain, opportunity for the child to live in normal family circumstances, and to be able to function socially, physically, psychologically and spiritually. While many disabled people enjoy a wonderful quality of life, this is not invariably so. I believe that as a society we should guard against the necessity for expecting all people to be 'perfect' and thus undervaluing disabled people. However as

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 far as possible quality of life should be a major consideration in determining treatment of a disabled neonate. Every person is a 'child of God' whether this is recognized or not. The child is infinitely precious both in life and in death. The faith of the parents may be a determining factor in how the treatment of the child is undertaken. I believe that the Working Party should include the role of the family in caring and coping with a disabled child. In my experience as a priest, a disabled child in the family is frequently a cause for family breakdown. I believe the mass media have often been unhelpful in decisions that have needed to be made. They are intrusive and often the facts of the case are misinterpreted and therefore they misrepresent the true implications of the case.

**Question 6**

**ANSWER:**

As I suggested in my response to an earlier question, sadly economic factors must be taken into account when deciding on the future of a severely impaired child's treatment.

**Question 7**

**ANSWER:**

Yes. Although perhaps the criteria will be somewhat different.

**Question 8**

**ANSWER:**

A framework of guidance might be very helpful to both doctors and parents. Yes, I believe that there is sufficient research now to suggest that very premature infants are disadvantaged well into teenage years. I believe the limit should be set at 28 weeks.

**Question 9**

**ANSWER:**

Probably not. It would be better to have a guidelines framework. Each case will need to be assessed on its circumstances within the guidelines.