

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 7

QUESTIONS ANSWERED:

Question 1

ANSWER:

This would depend on a number of factors, the main one being the end result. If the quality of life of the eventual child/adult is such as would prove to have some value to the individual concerned (such as the ability to feel love and loved, some happiness and a sufficient measure of awareness and achievement) then measures to save that individual would be justified provided they did not constitute an enormous amount of prolonged suffering in the process. However, survival at any cost and in any state seems hard to justify and it seems pointless and cruel to inflict such a 'life' on an individual who cannot in any way that we know experience any of the benefits of life as we understand it- for example, a person who is condemned to live in a heavily medical institution for life in a physical and mental state which doesn't allow him/her to enjoy/partake/recognise/feed etc. Another important factor would also be whether the parent(s) feel this is something they wish to enter into because the level of support provided to such a disabled person is crucial to achieve the potential benefits of their life. Parents may have a wealth of valid reasons (family, personal, economic or age related) which influence this. If there is a possibility of correcting the abnormalities before birth, then these should of course be taken as long as the corrections are not merely experimental and a support mechanism is in place to ensure that any possible long term damage caused by possible pain is in place. I do think there are some very rare occasions when the woman's wishes might need to be overridden though with a great deal of caution. These would be in circumstances as described in your note 10 or where the mother was not of sound mind or it was felt that the decision being made to keep the child was of no possible benefit to the child because of quality of life/suffering etc.... I do not think that a mother should ever be overridden if she does NOT wish to keep the child (providing she is within the law).

Question 2

ANSWER:

If practical or not totally ridiculous, the wishes of the parents should come first. The wish/will to support a child/adult in a severe condition is a very personal one for all the reasons outlined in Q1. All four of the circumstances above require an enormous amount of personal strength, commitment, money and time and affect the parents and any siblings very seriously. In all cases, the family might justifiably decide to let nature take its course. In the first medical intervention should certainly be given if desired by the parents because severely premature children do survive albeit with a number of possible problems. The nature of these potential problems are well documented and parents should be free to choose whether these are risks they wish to support-provided clear advice is given. Congenital abnormalities can still allow for a quality of life. Whilst some parents may not wish to continue the life of such a child, this may depend on the seriousness of the abnormalities. Many parents for example are happy to care for

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Downs syndrome children and certainly medical intervention should be offered in these cases but not imposed should parents decide they prefer to let nature take its course. The case becomes less clear in the next case where prospects are poor. Of course if chances are poor, it does not mean there is no chance and in such a case, medical intervention could be offered to try and save the child provided that the treatment is not experimental, will not cause long term suffering to the child and the outcome is worth fighting for. The same applies in the final case. The use of medicine in these cases is only really justified in the last two cases if the resulting child has a quality of life that provides some kind of human satisfaction/awareness/fulfilment and does not condemn the child to a life of hell, suffering, isolation, physical discomfort etc...to satisfy the emotional need of the parent.

Question 3

ANSWER:

1. I feel the moral status of the foetus is not something to be decided by 'society'. This is an intensely personal and private issue to which no two people can be expected to have similar views or beliefs. Religion plays a huge part in this for some, and as has been highlighted within your document, views differ and always will differ about when life really begins. Again, I feel this is not an issue that can be legislated and parents should be free to form their own judgements where severe circumstances arise. These will automatically influence their responses to point 2. 2. All these options are valid options. There is no such thing as 'not acting'. Not acting is still a choice in moral terms. In options b and c, it is well worth considering whether anyone has a right to let nature take its course if the baby is suffering when this could be avoided. Pain management for the child would be the crucial issue for discussion. Every parent has the right to decide to allow their child to die in these extreme circumstances but this does not give them the right to allow the child to die in severe pain when this could be avoided. All kinds of things are 'natural' but not necessarily desirable. 3. Questions of quality of life are the most important questions which need discussion. Quality of life covers a wide range of issues not only physical and mental for the child but for the parents and family too. No-one, not even a loving parent should have the right to impose a life of suffering and misery on a child/adult. A huge amount of support in helping parents to investigate their motives and the benefits to the child is needed. This is an area which is sadly lacking and needs urgent attention. The agony of a desperate parent watching their longed for child on the verge of death or a life of misery is beyond imagination. Little is done to help such people clarify what their thoughts and motives are and whose interests are being served by any particular course of action. An ethical question which has not been covered by this report is the one of twin or multiple births where one or more children are have severe disabilities/low life expectancy etc and the other(s) do not. It is possible to terminate one twin in the womb but this puts the other at risk of miscarriage or early birth and hence the high possibility of severe disabilities. The law does not provide for protection of this twin. Under the law, abortion is permitted up to 24 weeks unless two

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doctors agree to grant an extension. This extension cannot be given in order to allow the 'well' twin to go to term and live. It is based on the sick child and whether more time is needed after 24 weeks to assess the quality of life of the sick fetus. If it is the case that the position is clear before 24 weeks and the doctors will not sign off the extension, parents are forced into a position where they must decide to abort the sick fetus by 24 weeks putting the well fetus at grave risk of miscarriage OR keep both and risk giving birth to a severely disabled child when they had no wish to so but are forced into it in order to save the sibling. With the increased use of IVF, this situation is likely to happen more and more especially as IVF parents can be older and have higher risks of Downs babies. Some doctors simply sign off the extension letting common sense guide them and permit a later termination of the sick fetus claiming that they needed the extra time to assess them. The truth is that they wanted to save the well fetus. Others, uncomfortable with walking the knife's edge of the law, leave the parents with an impossible dilemma of all or nothing. This does need to be addressed because there are ethical questions in ignoring the well twins in these circumstances.

Question 8

ANSWER:

see my email

Question 9

ANSWER:

see my email