

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.

Mother Andrea Mrs., USA

QUESTIONS ANSWERED:

Question 2

ANSWER:

In all of these situations medicine and surgery should be used. My 23 week twin boys had undergone much medicine and many more surgeries. We were told that the lung disease alone may take the life on one and they were sure he would need to go home on oxygen. He is now home after 4 months in the NICU and he has not needed oxygen since he was 3 months old. There is no way to tell how a baby will come out of a situation... each baby is different. The staff said they were "sure"... but my baby proved them wrong.

Question 3

ANSWER:

Life is life the moment it is conceived. The quality of life is improved by the advancements in medicine. My son Seth (23 week twin) only survived 6 days he passed away from NEC/Septis. My son Jett is now 4 months old and we credit his little life to the advancements in medicine. We were told he would be blind from ROP... at 4 months old... NO ROP AT ALL! We were told he was so premature he wouldnt hear... he just passed his 2nd hearing test. We were told he could be on oxygen for months due to the sever BPD he has... he hasnt been on any oxygen since he was 3 months old. If it wasnt for surgery at 3 weeks old still under 2lbs for his open PDA... Jett would never had made it. He also has a shunt due to a grade 3 brain bleed. He has a "quality" of life... Seth his twin brother didnt make it... but... still he touched more lives than some people do in 60yrs... Jett on the other hand... did make it... and is one of the 30% of 23 weekers that survive.

Question 4

ANSWER:

"Quality of life" for one doctor could mean something completely different for a parent. Our NICU staff empowered us by allowing us to make descions about our 23 week twin boys. We lost Seth on the 6th day... I would do anything to be taking care of him... even if he was wheelchair bound. Jett is doing great... and the future I am sure will be full of surprises about his "quality of life" but we will take him anyway we can get him... and so far he has been a HUGE surprise to all the medical staff that was around him. Our spiritual influenes have got us through this. I believe that the Lord gave us Seth and Seth as I said touched more people in 6 days than some poeple can in 60 yrs. I believe that the mass media is helping the cause of these micro preemies as they show us even the smallest can survive... and thrive!

Question 5

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.

ANSWER:

The parents are the best judge for what "quality of life" they can handle. We knew that however Jett turned out was just the way the Lord entened for him to be. When families and professionals are involved it should be the parents decision on how to intervene. The family is the one that will be sent home with the baby and they love that child. I have found that the medical staff just views the baby as a patient... not a loved one. We were told at one point that our boys were doing so well that if we said "we are done... pull the plug" they would have been able to stop us as parents. In that case were the medical staff know and have seen babies make it in the condition they are currently in... the parents have to be overridden and the baby's life has to be saved.

Question 6

ANSWER:

A child from a poor background needs just as much of a chance as those from a previlaged background.

Question 7

ANSWER:

if the procedured is known to work... it should be used no matter what the cost.

Question 8

ANSWER:

There should NEVER be a set age to which to save a baby. If that were the case my 23 week twin Jett would not be here today. We have the medical technology to save these babies... and we need to use it. Everything so far that we were told would be "wrong" with our son... is NOT so! He has zero ROP... he hears fine... he can eat from a bottle he moves and he knows how to interact with others as well as he is strong enough to hold up his head and move where he wants it. He was only 23 weeks and he survived. His brother didnt... but... death is a part of life... rather we die at 6 days old of NEC/Septis/Extream prematurity... or if we die at age 10 from a car crash... neither may be "normal" ways of dieing... but they are both ways many have had to deal with death. Let nature take its course... but allow for the medical tecnology to help in anyway it can.

Question 9

ANSWER:

Every baby that is born needs the chance to live. Each baby is differnt. Out of my twin boys... the "healthy" one of the 2 passed away when he was only 6 days old. From all that had went on everyone including us as parents thought it would be baby 1 that would not make it. It is just to precious of a situation to make the decision for life for the babies... allow them to make that decision... not the government.