Dr Paul de Keyser, Specialist Paediatric Registrar

QUESTIONS ANSWERED:

Question 1

ANSWER:

I feel that there should be a greater equality of access for pregnant women to be able to consult those specialists who can best advise them on the extent of the likely fetal abnormalities , to enable those women to make their choices on an informed a basis as possible . While rotating through District general Hospitals ,I've sometimes felt that it has been difficult for pregnant women to get their review ,where it has been considered necessary ,at tertiary fetal medicine Units - although the quality of clinical care ,when they do see the patient ,has always been excellent . Overriding Wishes Where a pregnant woman may have mental health issues ,these have been well addressed in my clinical experience with liaison with the psychiatric specialists ,and if necessary the trust solicitors and the courts. But there remains uncertainty as to whether to begin to resuscitate a premature neonate at delivery ,where a pregnant women has asked that the baby not be actively resuscitated . While the gestation of the baby and the condition at birth both help inform the decision ,nevertheless the current lack of guidance in these - often unexpected - circumstances is a void that as a neonatal SpR I feel badly needs filling .

Question 2

ANSWER:

In each of these circumstances, if parents, appropriately counselled , would like the baby's doctors to continue to treat the baby actively , then I feel that initially such treatment should be offered , whether medical or surgical . Having worked as an SHO on a tertiary regional neonatal unit I witnessed several instances where active treatment was continued for the period that it took the parents to come around to the view that such treatment was either futile or intolerable for both their baby and themselves. I felt that by having given that treatment, baby’s parents would not forever be wondering “what if " and that in a small way this might help their grieving . But there surely does come a point - as in the Charlotte Wyatt and Luke Winston - Jones cases, where if clinicians feel that that certain interventions are not in the best interests of the baby, then involvement of the Family Court is justified if agreement cannot be reached with the parents.

Question 3

ANSWER:

As a clinician on a Neonatal Unit “Acting and omitting to act “is the most pressing ethical and legal issue that is constantly faced. Perhaps the working party can consider not just the ethics of the questions themselves, but also suggest how the NICU's can establish the mechanisms to enable the staff looking after a baby for whom the discontinuation of active treatment is a possibility, to discuss the ethical considerations amongst themselves in a structured way, rather than the sometimes haphazard coffee room discussions, which although valuable, are rarely shared with the oncoming teams

of the next shift .

Question 4

ANSWER:

Yes ,I do think that these are issues that should be considered . On several occasions I have found religious advisers invaluable in helping parents make decisions regarding life sustaining treatment. It would be enormously helpful if the Working Party could help promote two way education - for clinicians regarding the standpoint of different religious groups, and for clergy regarding some of the clinical issues often faced on NICUs. The impact of the media is, I feel, profound. Following the BBC Panorama documentary “Miracle baby grows up “of September 2004, it was evident, when counselling pregnant women on Labour Ward, who had gone into premature labour , that the program had been widely watched and had sharpened their awareness of the uncertainties of prognosis . I did feel ,however ,that difficulties arose when the guidance offered to these parents differed from their understanding of practice as portrayed on the program

Question 5

ANSWER:

On only one occasion have I been part of a clinical team that has needed to involve The Duty Social Worker ,and The Courts ,when parents have disagreed with the treatment proposed for their newborn baby .(The urgent need for an exchange blood transfusion for a severely jaundiced baby) . I was conscious that while we have protocols and guidelines for many things on The Unit, there was nothing regarding the process of Duty Social Worker involvement and beyond upon which we had to embark. Could the Working Party help promote education in this respect?

Question 6

ANSWER:

I feel that economic considerations play a significant role -as borne out by the difficulties sometimes inherent in seeking a cot in a tertiary Unit for a premature or otherwise sick neonate at a DGH. There is frequently a shortage of cots within reasonable travelling distance -particularly if it is a neonatal surgical problem. Perhaps the working party could look at how successfully Managed Clinical Neonatal Networks are working in facilitating the transfer of extremely premature infants from DGHs to tertiary units?

Question 8

ANSWER:

More guidance could be helpful, but perhaps not "directive" but more by contributing to establishing a framework which will allow clinicians and parents to decide what is in the best interests of the child and the family according to their own specific circumstances, rather than imposing a rigidity that might add to the anguish of their decisions. I do feel

that setting a minimum age would be mistaken .It could create the scenarios where a vigorous neonate just below the threshold may not be resuscitated ,yet at the same time creating the expectation that ongoing aggressive treatment should be delivered to those babies just above the threshold ,placing less regard on their condition at delivery . I do think that it is difficult to review the issue of “minimum gestation for resuscitation” without at the same time considering the laws on termination of pregnancies.

Question 9

ANSWER:

Yes, if the legislation contributes to creating a framework in which clinicians, parents and others can recognize the uniqueness of each case, and have the flexibility to respond to that. The RCPCH guidelines on "Witholding or withdrawing life sustaining treatment in children" are enormously helpful, but given the current challenge to the GMC guidelines on life prolonging treatment in the Burke case, it is important that the RCPCH guidelines do receive some form of statutory backing.