



Andrew Wilkinson

Professor of Paediatrics &
Perinatal Medicine,
University of Oxford
Neonatal Unit
John Radcliffe Hospital
Oxford
andrew.wilkinson@
paediatrics.ox.ac.uk

Dilemmas in the management of babies born at less than 26 weeks' gestation

The rapid advances in perinatal medicine during the last three decades have led to a range of new clinical and ethical dilemmas. Some of these are unique to the time of birth and none is more challenging than the decision to start or withhold resuscitation of an extremely preterm baby.

In developed countries the chance of survival for a baby born before term has improved dramatically. Reports from single centres, regional services and population based studies, although using different denominators, have confirmed the success that modern perinatal medicine has had at all gestational ages. In particular there is compelling evidence to show that survival of preterm babies is improved by the use of maternal antenatal steroid administration; postnatal artificial surfactant; modern artificial ventilation techniques and by the centralisation of intensive care with specialised nursing and medical staff.

As a direct result of this improvement in outlook for most preterm babies, attention is now increasingly focused on the most immature, those born extremely preterm. These babies, born at less than 26 weeks of gestation, have a high risk of death or moderate to severe morbidity¹. As a result a wide ranging debate is taking place which addresses the complex clinical aspects and ethical issues surrounding decisions which have to be taken by parents and healthcare professionals.

These issues are particularly pertinent in developed countries and have led to a number of important publications. In addition to the clinical concerns, discussion covers the ethical, social, economic and legal aspects. Apart from those isolated individuals who consider the newborn to have no consciousness, and therefore no rights, there is considerable general agreement among medical, nursing and lay people that consideration of the best interests of a baby must be a central factor in determining whether and how to treat him or her². There are however differences in the guidelines between countries, and between the views of healthcare professionals and parents, and few are specific about the appropriate role of parents in making decisions about withholding and withdrawing treatments³.

In common with the tenets of clinical practice, the ethical approach involves saving life, minimising suffering and enhancing outcome. With respect to the decisions to be made it would

be a lot more straightforward if babies could talk! Nevertheless, unique as it can appear, the concepts that apply have similarities at other stages of life when difficult decisions have to be taken.

The ethical, social and legal issues as they relate to the UK were recently extensively reviewed by a working party convened by the Nuffield Council on Bioethics and the conclusions are presented in detail⁴. The need for a team approach to decision making is emphasised. This should always include the healthcare professionals and the parents. This view is further emphasised by the British Association of Perinatal Medicine (BAPM)⁴.

Occasionally, extreme preterm delivery may take place precipitously leaving no time at all for discussion with the parents, but this is the exception. Possible transfer to another hospital within the network may be necessary. Every effort must first be made by the most senior professional responsible to become familiar with all the relevant information. Facts form the foundation of all good clinical (and ethical) decisions. The obstetric history needs reviewing with careful confirmation of the gestational age, which should be agreed with the mother. A coherent explanation of the most up-to-date and relevant information about expected short- and long-term outcome must be presented, while recognising that every pregnancy is different which makes precise prognosis difficult^{5,6}. In preparation for the range of events following delivery, the practicalities of starting, withholding and withdrawing intensive care, as well as the details of palliative care, must be discussed. A plan should be agreed and documented so others involved later are in no doubt about the decisions. Revision of the plan may be necessary if delivery does not take place.

Different cultural backgrounds must be respected and the support of family, friends and spiritual advisers encouraged. In circumstances where parents make it clear that they want doctors and colleagues to make the decisions, they should do so. The Nuffield report contains very useful clarification about the fundamental concept of 'best interests of a baby' as well as about issues which quite often appear to confuse clinical staff. For example, when after full assessment, often involving the opinion of a colleague, it is determined that a baby's condition is such that he or she will not survive, there is no legal obligation to proceed with treatment which is contrary to

their clinical judgement and considered futile.

Recognising a need for greater clarity over whether to initiate intensive care for these babies, the report recommended that "professional organisations within the UK, consulting with parents' groups, should develop guidelines..." The report contains only outline proposal for such guidelines.

To fulfil this work BAPM convened a group representing all the relevant professions with Bliss, the special care baby charity. Earlier this year their report was published as a comprehensive Framework for Practice⁴. This gives professionals a practical and clinical guide to best practice at the present time. More recently Bliss has formed a group to discuss ways in which the subject can be better presented to parents. This work will be completed toward the end of the year and will be a useful resource for all involved in counselling.

References

1. Wood N.S., Costeloe K., Gibson A.T., Hennessy E.M., Marlow N., Wilkinson A.R., EPICure Study Group. The EPICure study: associations and antecedents of neurological and developmental disability at 30 months of age following extremely preterm birth. *Arch Dis Child Fetal Neonatal Ed* 2005; **90**: F134-40.
2. Nuffield Council on Bioethics. Critical care decisions in fetal and neonatal medicine: ethical issues. 2006 www.nuffieldbioethics.org
3. Pignotti M.S., Donzelli G. Perinatal care at the threshold of viability: an international comparison of practical guidelines for the treatment of extremely preterm babies. *Pediatrics* 2008; **121**: e193-98.
4. Wilkinson A.R., Ahluwalia J., Cole A. et al. The management of babies born extremely preterm at less than 26 weeks of gestation. A framework for clinical practice at the time of birth. *Arch Dis Child Fetal Neonatal Ed* 2009; **94**: F2-5.
5. Watts J.L., Saigal S. Outcome of extreme prematurity: as information increases so do the dilemmas. *Arch Dis Child Fetal Neonatal Ed* 2006; **91**: F221-225.
6. Byrne S., Szyld E., Kattwinkel J. The ethics of delivery-room resuscitation. *Semin Fetal and Neonatal Med* 2008; **13**: 440-47.

Africa awaits YOU...



The Neonatal Nurses Association of Southern Africa (NNASA) together with The Council of International Neonatal Nurses (COINN) are proud to bring you the 7th International Conference of Neonatal Nursing 2010 for the first time on the African Continent.

Don't miss this opportunity! We look forward to welcoming you to Durban, South Africa, and our warm friendly rainbow nation.

Watch our website for further updates and booking:
www.nnasa.org.za or email nnasa@confco.co.za