

## Current topic

# ‘. . . officiously to keep alive’

C H M WALKER

Perth

Modern medical technology has provided powerful tools with which to initiate and sustain life and understandable concern is being expressed about scientists and doctors ‘playing God.’ The view that ‘the clinician’s freedom to stop intensive treatment when the probable outcome is severe handicap is part of the package of neonatology’<sup>1</sup> is far from unanimous. The hard facts are, however, that today up to 30% of deaths in a neonatal intensive care unit may follow deliberate withdrawal of life support<sup>2</sup> and despite concern for more than a decade<sup>3</sup> the ethics of this issue are still sub judice.

### The questions

Who is to say that procedures such as AID (artificial insemination by donor), IVF (in vitro fertilisation), or surrogacy are right or wrong? Who knows the wisdom or folly of saving the lives of thousands, even millions, who mankind cannot, or is not prepared to feed? How long should we live ‘aged and infirm’?

Not the least of these weighty questions is that of the justification of termination of life support in the newborn. While some advocate preservation of life at almost any cost others believe there is a time when ‘enough is enough’. But who decides? Some claim that not to try to preserve life is defeatist, denying progress, and morally wrong, yet by our interference with what might be regarded as a ‘natural selection’ are we creating more problems than we are solving? As with atomic energy, has society again been guilty of accepting the use of new procedures before either considering adequately the circumstances in which they should be used or the ethics of their use?<sup>4</sup> While everyone would agree that mortality statistics should never influence the initiation, continuation, or withdrawal of medical treatment, what of family disruption, availability of resources, cost effectiveness, and even the law?<sup>5</sup> The magnitude of these dilemmas and the interest they engender is illustrated by the fact that the whole of the June 1987 issue of *Clinics in Perina-*

*tology* is devoted to ethical and legal issues in that specialty.

### Ethics

With the exception of some forms of gross congenital deformity those attending a delivery *are now obliged* to resuscitate virtually all infants born around 22–24 or more weeks’ gestation. The frontier for survival has crept steadily down from 1000 g to 600 g birth weight over the past 10 years, though this of course is modified by the local facilities available. It no longer seems justifiable, therefore, to withhold this care purely on the grounds of gestational age or birth weight, or both, as babies of about this maturity survive at birth with assistance and can, though not always, grow up to be normal children.<sup>4,6</sup> But for those lives already established and being maintained artificially the decision to withdraw life support is more complex. To adopt the ‘near certain death or no meaningful life’ criteria<sup>2</sup> is a helpful approach for some, maybe for many, but there remain those for whom life in almost any form is sacred. Even the more radical views of the Roman Catholic Church leave room for judgment when it comes to using ‘extraordinary means’ to preserve life or where ‘a technique carries a risk or is burdensome in the light of likely benefit.’<sup>7</sup> Both the patient and others may be considered in this context and we are hearing a great deal more today about the ‘unremitting burden on carers’.<sup>8</sup> This presumes, however, that the newborn, not yet being a ‘person’ does not have similar rights to those of children and adults,<sup>1,9</sup> an assumption also challenged by all those who believe life and rights begin at birth, the age of viability, or even at conception.

Be this as it may it is surely acceptable to discontinue support when for a number of weeks, and it usually takes this long to be certain, a child has shown no potential for recovery and when sustaining life is merely prolonging the distress for parents and carers alike. It is of course wrong to assume that continued intervention can cause no

harm (an important ethical principle) as the complications of some life support measures are certainly harmful and the risk of trauma and/or other pathology may well increase with the duration of treatment. On the other hand, decisions to discontinue support are now strongly influenced by prediction, albeit imprecise, of the quality of future life. While prognosis is now reasonably accurate,<sup>10 11</sup> and will undoubtedly improve with future long term follow up data, the important question remains—is it better to be dead than handicapped?<sup>12</sup>

### Predictions

Before any decisions are made it is paramount that parents are given adequate and if need be repeated explanations of the medical problems, current and future. Breaking bad news is never easy but it pays to be gentle but frank and hope to win the parents’ trust about keeping them fully informed as to how the baby is progressing. It should be made clear that, despite all the technology and knowledge available, neither of the two principal indicators for the withdrawal of life support—near certain death and survival with severe handicap—can be foreseen with absolute certainty.

It has been suggested that there are ‘clinical categories’ for stopping treatment—severe asphyxia, preterm infants with major intraventricular haemorrhage, uncontrollable convulsions, and certain syndromes<sup>13</sup>—but these cannot in themselves constitute criteria. One recent study showed that even using significant predictors as indices, there was an error rate of at least 20% when attempts were made within 24 hours of birth to predict survival in infants less than 801 g.<sup>14</sup> Thus, with a few exceptions, the decisions about continuing intensive care should not be made until there has been a period of assessment and preparation. How long this should be depends on the individual case but in most instances this is measured in weeks rather than days.

The easy predictions are those where the baby has one of the readily recognisable congenital syndromes which are always associated with lethal anomaly or severe mental retardation, or both. In such cases primary resuscitation and life support are usually withheld from the outset. Syndromes with lesser and doubtful degrees of disability and those with acquired lesions leading to handicap pose more difficult problems which not infrequently resolve into an estimate of the degree of permanent damage.

There are as yet no established criteria of brain death in the newborn as those generally accepted in the adult are not applicable. Death can be anticipated with reasonable confidence, however, when

brain injury is so extensive that the pupils are fixed, where there is evidence of cerebral atrophy and failure of head growth, and the electroencephalogram shows no activity even on maximum stimulation. Serial tracings showing progressive deterioration are helpful<sup>13</sup> but the electroencephalogram is difficult to interpret in the newborn, especially if barbiturates have been given, and is even less reliable in the preterm infant. Death can also be anticipated when extensive lung damage is such that there is total dependency on a ventilator and where progressive increase in ventilation oxygen and pressure are causing further pathology. It can also be anticipated when lung destruction is associated with progressive and intractable respiratory failure or cor pulmonale. While it is also more likely in the presence of intractable renal failure or other severe metabolic imbalance, or both, these are, to some extent at least, correctable and are not good predictors. Hypothermia and sclerema, once thought to be ‘terminal’ and fused eyelids, once thought to indicate previability, do not, with modern treatment, indicate early demise.

Assessment of the extent of brain damage and its relation to future handicap is becoming rapidly more accurate as, in skilled hands, the various types of scanning image now correlate well with necropsy findings. Extension of intraventricular haemorrhage into the cortex and bilateral periventricular leucomalacia are usually associated with severe degrees of handicap, though such an outcome does not necessarily follow intraventricular haemorrhage or ventricular dilatation. Less precise still are the predictions about the long term effects of cerebral oedema or imbalance of glucose, sodium, and other electrolytes. The value of enzyme assay, brain stem evoked responses,<sup>13</sup> and carotid artery flow measurements as predictors of severe permanent brain damage and handicap have yet to be fully clarified but so far none have shown great promise.

‘When in doubt—don’t!’ may seem a crude philosophy in this situation but while doubts about the life and the extent of damage in survivors should be admitted and discussed with the parents they should preclude any mention of withdrawal of treatment until they have been resolved sufficiently for the caring team to reach a decision among themselves.

Medical and nursing staff must realise, however, that parental understanding of the full impact of the situation after the first or even further consultations may be negligible. The skill is in the recognition of the parent(s) who take in the implications of what has been said and those who block them or fail to grasp the situation. Only when the caring team feel they really understand, or understand as much as

they ever will, should the possibility and timing of withdrawing life support be discussed.

No matter what the doubts and uncertainties that doctors may still have about the likelihood of death and/or handicap they must, having made a decision with their team as to what they believe to be in the best interests of the baby and family, give positive, unequivocal, and convincing advice to the parents.

It should be explained that on withdrawal of the ventilator the baby may go on gasping for a little while and that, rarely, the baby may establish respirations and survive. While the latter possibility should be mentioned, too much should not be made of it lest parents raise too many false hopes. In the event of unexpected survival there is no virtue in the doctor doing anything but admit he did not expect the baby to manage on his or her own, and for those doctors and parents with a religious faith comfort is to be found in the belief that the baby was perhaps just 'meant to live' no matter what the future holds. Parents must of course be reassured immediately about the support they will receive in the event of long term survival with handicap.

### Decisions

Once the team feel that the period of discussion and explanation has been adequate and that the parents are ready to face the prospect of the death of their baby the possibility of turning off the ventilator can be raised. The parents should be told that the team feel the time has come to 'let nature take its course,' that everything possible has been done for as long as is necessary to know that the baby has little or no chance of survival let alone of having a happy even near normal life. Eventually the question should be put as to whether the parents would consider such a step yet or would they prefer to continue the ventilation for a little longer.

Opinion as to who should make the final decision to terminate treatment seems to vary.<sup>15</sup> Some professionals think that after adequate discussion and counselling the parents should make the decision. Some parents feel they have this right and wish to exert it while others thought in retrospect that they had made the decision when in fact they had merely accepted the doctor's advice.<sup>13</sup> Others would go so far as to say that it is 'intolerable for parents to have to be responsible for such decisions' and as it is the doctors who understand the risks and limitations of intensive care procedures it is they who must be responsible for their initiation and withdrawal.<sup>16</sup> I believe that it is better, after unhurried consideration by a group comprising parents, nursing staff, family doctor, social workers and, if the parents so wish, someone from the chaplaincy, for the doctor

to make the concluding suggestion that it is timely to withdraw support and invite the parents to agree or disagree. In this way the parents are to some extent relieved of the possible distress of, at a later date, regretting that they alone had decided to let their baby die. Is it not better to have them remember the discussion team making the overture, their own part being that of taking the best advice available at the time?

Should the parents wish treatment continued then the decision is, for the time being at least, easy but another opinion should be procurable and offered if they show the least signs of uncertainty about the advice being given. Whether this should be consultation with another similar but clinically uninvolved group or a formal bioethics committee is a matter for local arrangement.<sup>4 17</sup> While rigid rules for decision making in this situation are quite inappropriate conclusions should nonetheless be reached in the open and without coercion or conspiracy.<sup>4</sup>

### Preparation for loss

Preparation for the event of death eases the blow when it comes and the rational participation of parents in decision making is possible despite their grief.<sup>18</sup> Paediatricians are sometimes reluctant or feel unable to discuss life and death or life hereafter<sup>19</sup> but no matter what their own beliefs may be they should have someone on their team who can talk with parents about these matters before and after the event of the death of their baby. While doctors can usually explain the mechanism of death these other and fundamental questions still remain unanswered and what the medical and nursing staff think about such matters personally is irrelevant. The questions such as 'Why us?', 'Why our baby?' are unanswerable but some parents find solace in the belief that God has a plan which they may not understand but which their faith helps them to accept.

Sometimes the parents ask for treatment to be stopped and they may do this too early or quite inappropriately. They don't think of this as killing, although of course there are members of our society who do. On the one hand it is understandable that parents cannot stand the strain of waiting for the unknown; the days, weeks, or even months of not knowing if they will in the end have a live baby. Some don't want to face the risk of the survival of an abnormal child and a few just didn't want the baby in the first place—and still don't. On the other hand most will leave no stone unturned before reaching the painful decision to agree to termination of care. It must be a rare event indeed that life support is

terminated inappropriately early or without due consideration, but unfortunately there are clandestine groups of which paediatricians have become only too aware who are eager to report clinical action of this nature to the police if they think it is contrary to their beliefs.

Nowadays most parents, usually the mothers, wish to hold their babies at the time of withdrawal of life support, being assured that at no time is care in the form of warmth, comfort, control of pain, and nutrition withheld. There should be sensitive and unhurried discussion about this event and about arranging the 'last rites', family visits, final photographs, and other practical details before action is taken. Parents should have no anxieties caused by lack of knowledge of what happens to the baby's body, how they contact the undertaker and what it is all going to cost—factors which caring teams have in the past tended to neglect.

Each case is unique and must be treated as such and the decision to terminate care influenced mainly by the moral and ethical codes of the society and the parents involved. The parents should of course be invited, but not pressurised, to return in a few weeks for a further discussion about the causes of death and the necropsy results and to discuss with the obstetrician the prospects for future pregnancies.

### The future

With rare exceptions initial resuscitation is advisable as this gives valuable time to make detailed clinical assessments and to prepare the family for their loss. Long term developmental studies will provide yet more accurate information about prognosis after threatening episodes such as intraventricular haemorrhage, leucomalacia, convulsions, and metabolic imbalance. As predictions about an infant's future capabilities improve so will the medical attendant have greater confidence in the advice offered.

The final hurdle, however, is to obtain 'permission' from society for the medical profession to adopt some code of practice which will give the paediatrician confidence that if and when support is discontinued after an approved procedure involving a period of medical treatment and joint consultation he will not be under threat of fiscal action.

The arguments as to whether there is any moral difference between 'killing' and 'allowing to die' have little relevance as there is already a widespread though not total social acceptance of the latter for which criteria of moral justification and legal acceptability are still required.<sup>9</sup> As Dame Mary Warnock puts it '... doctors ought to be given a general rule for the management of ill babies.'<sup>16</sup>

A start has been made to provide the profession with guidelines for protection in law in the form of an independently proposed 'Draft Limitations of Treatment Bill.'<sup>20</sup> This outlines the circumstances under which it would *not* be an offence to withhold or withdraw treatment in the newborn. Some of the provisions include, for example, that the infant should be under 28 days of age; that parents have given written consent; two doctors (one a paediatrician) of not less than seven years standing willingly give a written statement as to the medical status of the baby—for example, the irreversible nature of the condition or unavailability of further treatment, the expected quality of life, taking into account the pain and suffering of prolonging treatment—for example, repeated surgery—the attitude of and effects of prolonging care on the family, and the willingness and ability of the family to provide long term support in the event of handicap. Food and sustenance would, however, be continued unless its provision would directly increase the degree of pain and suffering. The fact that this draft bill has not so far been taken up either by the government or any member of parliament as a private members bill raises a number of questions. Are paediatricians considered as already acting with sufficient expertise, wisdom, and good faith that no change in the law is required? Is what the caring teams are doing acceptable even though they are regarded by some as immoral and unethical and skirting the edge of the law? Do the law makers support the belief that to legislate would set arbitrary or even unworkable rules which could make things more difficult for the profession rather than less?<sup>21</sup> Or is it that there is so much difference of opinion that they believe it to be virtually impossible to formulate policies which would satisfy a majority?

Meantime the paediatrician caring for the newborn is caught in the middle—damned by some if he does preserve life, accused of enthusiastically using his high technology regardless of the quality of life preserved, and damned by others if he doesn't, branded as guilty of euthanasia or even murder—in limbo, encouraged by the majority of society, but unprotected by the law.

The Bioethics Committee of the Canadian Paediatric Society has proposed criteria which forbid hastening death in any way but consider withholding care if (a) there is irreversible progress of disease or imminent death; (b) treatment will be ineffective or harmful; (c) life will be short, even with treatment and where nontreatment will permit more comfort and caring; and (d) future life will entail intolerable pain and suffering. Other, though very similar, guidelines have been suggested in the United States<sup>13 22</sup> and now in the United Kingdom<sup>20</sup>



but in the end the criteria are established and the clinical decisions are made locally in the light of the circumstances of each individual case with the careful balance of potential immediate and long term risk against potential survival and lifestyle. I believe that ethical committees should not take part in what is a very complex but personal decision but have a watchdog role and be called upon in the event of indecision or dispute. Precise regulations are unlikely to be sufficiently flexible for these multifaceted and highly individualised situations and many will share the concern over the restrictions which legislation might impose.<sup>21</sup> It is surely timely, however, for doctors and lawyers together to pursue, though not necessarily in haste, the composition of a generally acceptable code of conduct for the guidance of both professions.

For example:

- (1) The caring team should consider the case in the light of the four criteria proposed by the Canadian Paediatric Society (above).
- (2) A second doctor (consultant paediatrician or principal in general practice) should agree to and cosign a statement describing the clinical status of the baby and the reasons for recommending withdrawal of care.
- (3) After preparatory talks and when the caring team regard the parents are ready a case conference should be held involving the parents, caring team, family doctor, social worker, and if desired by the parents a member of the chaplaincy at which these circumstances (see (2) above) are explained and withdrawal of care is suggested to the parents.
- (4) If they agree, this is minuted and signed by the conference leader. (Parents should not be asked to sign as this is distressful and there is no need when their agreement is witnessed by so many people and documented.) A smaller, less formal and more intimate meeting to describe what actually happens and to learn what the parents would like to happen is planned to follow as soon as possible.
- (5) If they are unsure or disagree, treatment is continued and another medical opinion is offered.

Though such guidelines have no legal standing they could at least give doctors a set of general ground rules concerning the process which should be followed before, during, and after withdrawing intensive care and give the lawyers a similar guide as to what they consider should have been done in the

event of cases coming to court. This common understanding could perhaps give paediatricians a degree of protection from the crossfire to which they are currently exposed and go some way towards smoothing if not completely calming these troubled waters.

#### References

- <sup>1</sup> Bissenden JG. Ethical aspects of neonatal care. *Arch Dis Child* 1986;**61**:639-41.
- <sup>2</sup> Whitelaw A. Death as an option in neonatal intensive care. *Lancet* 1986;ii:328-31.
- <sup>3</sup> Duff RS, Campbell AGM. Moral and ethical dilemmas in the special care nursery. *N Engl J Med* 1973;**289**:890-4.
- <sup>4</sup> Kohrman AF. Selective nontreatment of handicapped newborns: a critical essay. *Soc Sci Med* 1985;**20**:1091-5.
- <sup>5</sup> Bioethics Committee, Canadian Paediatric Society. Treatment decisions for infants and children. *Can Med Assoc J* 1986;**135**:447-8.
- <sup>6</sup> Dunn PM, Stirrat GM. Capable of being born alive? *Lancet* 1984;i:553-5.
- <sup>7</sup> Gillon R. Ordinary and extraordinary means. *Br Med J* 1986;**292**:259-61.
- <sup>8</sup> Goodall J. Ethical dilemmas in neonatal care. *Maternal and Child Health* 1984;**9**:276-9.
- <sup>9</sup> Gillon R. Conclusion: the Arthur case revisited. *Br Med J* 1986;**292**:543-5.
- <sup>10</sup> Fawer CL, Diebold P, Calame A. Periventricular leucomalacia and neurodevelopmental outcome in preterm infants. *Arch Dis Child* 1987;**62**:30-6.
- <sup>11</sup> Palmer P, Dubowitz LMS, Levine MI, Dubowitz V. Developmental and neurological progress of preterm infants with intraventricular haemorrhage and ventricular dilatation. *Arch Dis Child* 1983;**57**:748-53.
- <sup>12</sup> Watkins A. Prognosis for infants born 23 to 28 weeks gestation. *Br Med J* 1987;**294**:373-4.
- <sup>13</sup> Ragatz SC, Ellison PH. Decision to withdraw care in the NICU. *Clin Pediatr (Phila)* 1983;**22**:729-35.
- <sup>14</sup> Zarfin J, Acrcde JV, Perlman M, Pape K, Chipman M. Predicting survival of infants less than 801 grams. *Crit Care Med* 1986;**14**:768-72.
- <sup>15</sup> Singer P. Neonatal intensive care. How much, and who decides. *Med J Aust* 1985;**142**:335-6.
- <sup>16</sup> Warnock M. Medical advances bring ethical responsibilities. *The Listener* 1987; June 4, **117**;No 3014:8-9.
- <sup>17</sup> Berseth CL. Ethical dilemmas in the neonatal intensive care unit. *Mayo Clin Proc* 1987;**62**:67-72.
- <sup>18</sup> Benfield DG, Lieb SA, Vollman JH. Grief response of parents to neonatal death and parent participation in deciding care. *Pediatrics* 1978;**62**:171-7.
- <sup>19</sup> Kepler MO. The religious factor in pediatric care. *Clin Pediatr (Phila)* 1970;**9**:128-30.
- <sup>20</sup> Brahams D, Brahams M. The Arthur case—a proposal for legislation. *J Med Ethics* 1983;**9**:12-5.
- <sup>21</sup> Havard J. Legislation is likely to create more difficulties than it resolves. *J Med Ethics* 1983;**9**:18-20.
- <sup>22</sup> Milligan JE, Shennan AT, Hoskins EM. Perinatal intensive care: where and how to draw the line. *Am J Obstet Gynecol* 1984;**148**:499-503.

Correspondence to Dr CHM Walker, 2 The Stables, Pitfour Castle, Glencarse, Perth PH2 7NJ.