Guidance for withdrawal and withholding of intensive care as part of neonatal end-of-life care

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Introduction: Advances in foetal medicine and neonatology have enabled increased antenatal diagnosis of life-limiting conditions and improved preterm survival, escalating the debate surrounding the ethics of neonatal end-of-life care and withholding or withdrawing intensive care.

Sources of data: Literature search of MEDLINE and the Cochrane library databases using the search terms [neonatal palliative care] AND [neonatal AND withdrawal of intensive care and treatment]. Review of consensus statements and guidelines.

Areas of agreement: UK practice is aided by Grade 3–4 evidence, consensus statements and practice frameworks. There is limited systematic evidence.

Areas of controversy: We illustrate UK practice with clinical cases and describe worldwide variations.

Growing points: Neonatal end-of-life care incorporating withholding and withdrawing intensive care is not uncommon. The child’s ‘best interests’ take precedent and clinical guidance has been published to support the joint decision-making partnership of clinicians and families. Withholding and withdrawing intensive care should be part of an overall end-of-life care plan incorporating the principles and standards of palliative care.

Areas timely for developing research: Further guidance on standards and staff training with regard to communicating and delivering neonatal end-of-life care is required to ensure consistent practice of staff and choices for families. The recommended establishment of neonatal outcome databases should aid UK preterm decision-making (NHS and Department of Health Neonatal Taskforce, Toolkit for high-quality neonatal services, London, Department of Health 2009).

Keywords: neonatal/palliative care/withdrawal/intensive treatment

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Introduction

Technological advances in neonatology increasingly allow us to resuscitate and sustain life where previously a baby may have been deemed ‘too early’ or ‘too sick’. Whilst antenatal steroids and endotracheal surfactant administration have improved the survival rates of premature babies,\textsuperscript{1,2} there has been no improvement in the incidence of developmental disabilities amongst extremely preterm survivors.\textsuperscript{3,4} Advances in foetal medicine have enabled increased antenatal detection of lethal or serious foetal abnormalities. Parents then face the difficult decision as to whether to continue the pregnancy or opt for a medical termination.

Following the birth of an infant at the threshold of viability (\( \leq 25 \) weeks and 6 days, as defined by the Nuffield Council of Bioethics), or a birth where a serious congenital abnormality has been diagnosed, clinicians are confronted with an ethical and legal dilemma:

(i) To institute life-saving measures at the extremes of viability, commencing a prolonged course of intensive care, with the knowledge that most survivors incur severe and/or moderate disability (Table 1).

(ii) To provide intensive management for a serious antenatally diagnosed condition, thereby delaying death.

(iii) To withhold life-saving measures from the outset and offer palliative care.

(iv) To initiate treatment and withdraw later.

<table>
<thead>
<tr>
<th>Table 1 Summary of EPICure outcomes for all live births at (&lt; 26 + 0) weeks’ gestation in the UK and Ireland, March to December 1995.</th>
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</thead>
<tbody>
<tr>
<td><strong>Outcome</strong></td>
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<tr>
<td></td>
</tr>
<tr>
<td>Live births</td>
</tr>
<tr>
<td>Died in delivery room</td>
</tr>
<tr>
<td>Died in NICU (% admitted)</td>
</tr>
<tr>
<td>Survived to discharge (% survived)</td>
</tr>
<tr>
<td>Severe disability (% of survived to discharge)\textsuperscript{a}</td>
</tr>
<tr>
<td>Moderate or mild disability (% of survived to discharge)</td>
</tr>
<tr>
<td>Survivors without identified impairment at 6 years (% of live births)</td>
</tr>
<tr>
<td>Survivors without identified disability at 6 years (% admissions)</td>
</tr>
</tbody>
</table>

Adapted from ref. (7).

\textsuperscript{a} Severe learning problems, non-ambulant cerebral palsy, profound deafness, blindness.
These difficult decisions, which may evolve over the neonatal course, should be made in a clinician–parent partnership, with the infant’s ‘best interests’ being paramount. Few standards exist for the growing area of neonatal palliative care. Guidance on the delivery of neonatal palliative care is emerging most recently from Association for Children’s Palliative Care (ACT), British Association of Perinatal Medicine (BAPM) and Bliss. This paper aims to review the ethical and practical issues of neonatal end-of-life care and to present current UK and international practice. Clinical examples illustrate the ethical dilemmas facing neonatal teams.

Methods

A literature search of MEDLINE and the Cochrane library databases using the search terms [neonatal palliative care] AND [neonatal AND withdrawal of intensive care and treatment] was conducted. We also reviewed UK consensus statements from the following groups:

(i) Royal College of Paediatrics and Child Health (RCPCH).
(ii) Nuffield Council on Bioethics.
(iii) British Association of Perinatal Medicine (BAPM).

Results

There is a paucity of objective, systematic evidence to aid neonatal critical-care decision-making. We found no meta-analyses or randomized controlled trials. One-hundred and sixty-seven review articles were available of which 12 abstracts were relevant. This evidence is Grade 3–4 only. Further papers were sourced from references in available review articles. We discuss below present practice with regard to the limited evidence-base and guidance from professional groups.

Discussion

European law states that any person has a right to life from the moment of birth. The neonatal period is conventionally defined as the first 28 days of life. For the purposes of this article, we refer to children as individuals older than a year and younger than 18 years of age.

Historically, the concept of protecting the ‘sanctity of life’ was borne from Ancient Greek ideals. However mentally/physically impaired infants were left to die through exposure and Hippocrates himself
argued in support of withholding treatment where there was incurable disease. Sir Thomas More postulated a Utopian ideal where ‘torturing and lingering pain’ could be ended, although this was the anti-thesis of Christian doctrine. In the USA, ‘passive killing’ was reported in the 1915 press regarding an infant with multiple ‘defects’ and a baby with hydrocephalic spina bifida. A coroner’s jury of physicians concluded that the physician had acted ‘within his ethical and moral rights’. During the 1970s, follow-up studies of children with severe spina bifida found that, despite surgical intervention, children had severe brain damage and physical disability, prompting discussion that death should be allowed to occur naturally without medical treatment. In the mid-1980s, following two high-profile cases of non-treatment for an infant born with Down’s syndrome and trachea-oesophageal fistula and an infant with spina bifida, the US government attempted to include the withholding of treatment from disabled children within its definition of child abuse. Concurrently, a UK neonatologist admitted on television to withdrawing ventilatory support for extensively brain-damaged infants, opening the debate further.

In 1997, *Pediatrics* published a study reporting that ‘limiting treatment’ was the major cause of death in the neonatal intensive care unit. The same year the RCPCH produced a framework summarizing the following: ‘…all members of the health team, in partnership with parents, have a duty to act in the best interests of the child. This includes sustaining life and restoring health to an acceptable standard. However, there are circumstances in which treatments that merely sustain ‘life’ neither restore health nor confer other benefit and hence are no longer in the child’s best interests’. General Medical Council guidance went on to state that ‘there is no obligation to give treatment that is futile or burdensome’. Therefore, clinicians are legally supported in withholding/withdrawing care which is not considered in the best interests of the child.

RCPCH guidance describes five situations where the withholding or withdrawal of life-sustaining care to ‘children’ is deemed appropriate. Although neonatal withdrawal of care is often extrapolated from this guidance, points (iii)–(v) below are the most commonly invoked:

(i) The ‘brain dead’ child. The diagnostic criteria for *neonatal* brain death, let alone in a premature neonate, is controversial and beyond the scope of this article.

(ii) The ‘permanent vegetative’ state. For example, the withdrawal of artificial ventilation from a term baby who has suffered birth asphyxia and clinical examination and investigation has revealed profound brain damage.
(iii) The ‘no chance’ situation. The child has such severe disease that treatment fails to alleviate suffering, but serves to delay death. For example, a baby born with anencephaly.

(iv) The ‘no purpose’ situation. Survival would involve physical/mental impairment that is so great ‘it would be unreasonable to expect them to bear it’. For example, the decision to withhold resuscitation in a baby born at 23-week gestation.

(v) The ‘unbearable’ situation. ‘The child/family feels that in the face of progressive and irreversible illness further treatment is more than can be borne’. For example, withdrawing respiratory support from an infant found to have Zelwegger’s syndrome.

In 2006, a report from the Nuffield Council on Bioethics addressed the complexities of foetal and neonatal critical-care decision-making in great depth. The report was collated over 2 years and involved a multi-professional working group and public discussion. It addresses the complexities of foetal medicine, the notion of borderline viability and babies receiving intensive care. It forms the background to the BAPM’s Clinical Practice Framework for deliveries occurring at >26 weeks. The latter provides guidance to UK neonatal practitioners regarding extreme prematurity and end-of-life care. We refer to these seminal documents throughout this paper.

Managing extreme prematurity

In the event of threatened preterm labour, the majority of mothers will present to a district general hospital. The obstetric team should communicate early with the neonatal team as to whether in utero transfer to a regional neonatal unit is appropriate. The neonatal team should ascertain the obstetric history of the mother and gestation of the infant. Particular attention should be paid to any discrepancy with regard to dating and gestation. Recent growth scans/estimated foetal weight can be useful as the outcome of premature babies with foetal weights <500 g are particularly poor. It should also be noted whether the mother has received antenatal steroids. A discussion should then follow between the parents and neonatal team (ideally, with the most senior clinician available at the time).

Parental counselling and outcomes of prematurity

In the majority of premature births, there is usually adequate time to provide parents with information about possible outcomes for their baby and to discover their expectations and wishes. The intention of
counselling is for parents to feel sufficiently informed to be able to contribute to decision-making. A Canadian study of parental and clinician feedback suggests that parents prefer to receive more than a neutral, fact-based discussion and would rather engage in a supportive, joint-management discussion.\textsuperscript{16}

Outcome information discussed with parents is based upon mortality/morbidity studies and follow-up statistics. The difficulty in predicting outcomes for their individual infant should be explained to parents. The EPICure study\textsuperscript{17} looked at all deliveries in the British Isles and Ireland from 20 to 25 weeks gestation over a 10 month period in 1995. The study was repeated in England in 2006 (EPICure 2) with preliminary results showing an improvement in ‘survival’ at 24- and 25-week gestation (Fig. 1). Peer-reviewed publication of follow-up morbidity data is eagerly awaited. As the EPICure data series was pooled from 276 maternity units, it is generally considered the most representative of UK outcomes. The media has argued that this data may not necessarily reflect practice at so-called ‘centres of excellence’. Parliament recently debated preterm viability and a lowering of the abortion limit. This was ultimately rejected.\textsuperscript{18} When parents request survival/disability data, clinicians should be aware of the limitations of single-centre outcome data and the importance of using population-based data.\textsuperscript{19}

Decisions made before delivery are provisional and an essential part of counselling is to warn parents about their baby’s possible condition at birth. It should be made clear that the infant’s condition is highly influential in decision-making and delivery-room care. Common

\begin{figure}
\centering
\includegraphics[width=0.5\textwidth]{fig1.png}
\caption{Babies admitted for intensive care in England in 1995 compared with preliminary data for 2006. Reproduced from www.epicure.ac.uk/overview/survival with permission from Professor Neil Marlow.}
\end{figure}
criteria used to inform decision-making include movement of the neonate, lack of bruising, presence of spontaneous respiratory efforts and response to initial resuscitation. Figure 1 shows outcomes for babies ‘admitted’ to NICU. A large proportion of babies will die in the delivery room (Table 1).

Parental views may differ widely. A mother who has three healthy children may feel that the risk of neurodisability associated with intensive resuscitation of a 24-week infant is too high and would prefer to give comfort care only. What does the clinician do when faced with a good heart rate and gasping infant who is 24 weeks? Similarly, a mother in her late forties who has had multiple miscarriages may wish the medical team to aggressively manage her 23-week baby. How does the clinician proceed following the birth of her infant who has a heart rate of >60 and who is not breathing? The BAPM has provided guidance on the management of infants at <26-week gestation to support medical decisions (Table 2).

Withdrawal and withholding of intensive treatment

The withdrawal and withholding of care has been reported in neonatology for over 30 years. ‘Withdrawal’ of life-saving treatment implies the elective discontinuation of ongoing life-supportive measures. ‘Withholding’ of treatment occurs when interventions necessary for immediate survival, such as surgical intervention or resuscitation (bag and mask/endotracheal ventilation, cardiac massage or adrenaline) are deliberately not administered.

Withdrawal of treatment most commonly takes the form of withdrawing of ventilatory support. In the extremely premature neonate who has had poor response to bag and mask ventilation, this may

Table 2 Summary of ‘Management of babies born extremely preterm at <26 weeks of gestation: a framework of clinical practice at the time of birth’.

<table>
<thead>
<tr>
<th>Gestation</th>
<th>Caesarean section</th>
<th>Care</th>
</tr>
</thead>
<tbody>
<tr>
<td>&lt;23 weeks</td>
<td>Maternal indications only</td>
<td>Resuscitation would not normally be carried out</td>
</tr>
<tr>
<td>23 + 0– 23 + 6</td>
<td>Maternal indications only</td>
<td>Assessment and care consistent with parents wishes</td>
</tr>
<tr>
<td>24 + 0– 24 + 6</td>
<td>Rarely indicated</td>
<td>Resuscitation followed by reassessment</td>
</tr>
<tr>
<td>25 + 0– 25 + 6</td>
<td>Should be considered if foetal compromise occurs</td>
<td>Resuscitation and intensive treatment</td>
</tr>
</tbody>
</table>

*Survival and outcome of infants born at 23 + 0–24 + 6 is poor. Management of infants born at this gestation should be consistent with the parents’ wishes, but decisions made before birth are influenced by the baby’s condition at birth….*
mean stopping ventilation breaths, explaining to the parents the reason for discontinuation and offering comfort care according to the parents’ wishes. Parents should be prepared for the sequelae that may follow withdrawal from mechanical ventilation. The infant may become agitated secondary to hypoxia, display terminal gasping and, depending on the size and gestation of their infant, tachypnoea, intercostal reccesison or stridor may be evident. Parents may want to be involved in the extubation process. Following ventilator withdrawal, the length of time prior to death cannot be predicted and can be a significant cause of parental anguish if this is not explained. A side room and privacy should be made available for the family. NICE guidance suggests that women ‘should not be encouraged to hold their dead baby if they do not wish to’, although this is very much dependent on individuals.

‘Non-escalation of therapy’ is a method of minimizing intensive treatment. Examples of this may include continuing with CPAP (continuous positive airway pressure) via a mask but deciding not to instigate intubation or inotropic support, should further deterioration occur.

Clinical case: A mother presented to labour ward in active labour at 24 + 2 weeks gestation. Rupture of membranes had occurred at 20 weeks. The mother received antenatal counselling detailing the likely poor prognosis of her baby. A male infant (birth weight, 640 g) was delivered with an audible but slow heart rate on initial assessment. This responded to bag and mask ventilation to a maximum of 60 beats per minute. In view of the poor response to resuscitation further intensive treatment was withheld and baby was given to the parents to hold. The baby died a short time later.

Comment: Further care was withheld as per RCPCH guidance: ‘no purpose’.

Determining the ‘best interests’ of the infant can be challenging. For example, most infants with chronic lung disease have a relatively benign course. In a minority of cases, bronchopulmonary dysplasia progressively worsens requiring ongoing ventilatory support. Neurological prognosis may be good or, more commonly, unclear. If medical intervention is likely to prolong death rather than offer any reasonable chance of survival then withdrawal of treatment may be considered in the best interest of the child, despite no clear evidence of neurological impairment. A more ethically unclear situation arises when the baby is not currently ventilated but is deteriorating and is likely to require further respiratory support with anticipated ventilator dependence. It may be considered appropriate to withhold further respiratory support in view of the overall poor prognosis.
A similarly difficult scenario is the term baby with a very poor neurodevelopmental prognosis who may stabilize with intensive therapy. The window for withdrawal of intensive treatment can be narrow. If this is delayed, the baby may survive extubation with profound neurodisability, despite the parents and clinician’s wish to withdraw intensive treatment.

Clinical case: A term baby with multiple abnormalities was born to consanguineous parents. He was ventilated for 3 months pending extensive metabolic and genetic investigations, which were initially inconclusive. Following extensive discussion between staff and family, intensive care was withdrawn. The final diagnosis following death was Bowen-Conradi syndrome, a rare autosomal recessive lethal condition.

Comment: Care was withdrawn as per PCPCH guidance for the ‘unbearable situation’.

Palliative care and bereavement

Palliative care has been defined as the ‘Active, total care of patients whose disease is not responsive to curative treatment. The goal of palliative care is achievement of the best quality of life for patients and their families’.6 Palliative care should be considered as care during the period of supportive and end-of-life care. The period of survival before the end-of-life period can vary from minutes to hours, days, weeks or months. Withholding and withdrawing of intensive care will form part of an overall palliative care plan incorporating supportive and end-of-life care. The recent BAPM framework for perinatal palliative care describes stages of palliative care that should be considered when agreeing a care plan with families. This includes the period of transition from routine clinical care to palliative care. The period of supportive care requires consideration and planning for specific clinical aspects such as oral nutrition and hydration, investigations, treatment and monitoring, pain relief and analgesia. The Nuffield Council on Bioethics review states ‘oral nutrition and hydration should only be withheld from a baby when it is clear that providing it causes discomfort and pain’. Opiates are commonly prescribed to alleviate pain. It is illegal, however, to administer a drug with the intention of shortening life, although it remains lawful if death results as a side effect when relief of pain was the intention6,13. This double effect of analgesia is well described. The use of muscle relaxants during neonatal ventilation is commonplace but their palliative use is controversial.23 They may
hasten death and it is debatable as to whether they reduce terminal (agonal) gasping.

Throughout palliative care planning communication and documentation of plans should be made with all members of the acute and community health-care teams. The general practitioners (GP) should be updated at all times. Involving the paediatric palliative care team or hospice should be considered as early as possible for babies who will have their end-of-life care at home or in a hospice. The mainstay of good palliative care is to provide support to the family and baby as a whole. A care plan should be agreed with the parents until the event of their baby’s death. On occasion an infant may be discharged home for palliative care in the community, e.g. a baby with spinal muscular atrophy. This can be successfully provided if communication between hospitals, GP and community teams and the family is clear. This should include guidance regarding their baby’s expected deterioration and symptom management.24

Care after death should be specifically planned for with families. Parents will continue to need support with the initial arrangements required after death, e.g. funeral, registration of death. Most neonatal units offer bereavement care, such as bereavement photography, counselling and the creation of a mementoes box. Harvey et al.21 recently reviewed bereavement practice, noting that most interventions are ‘compassion led’ rather than evidence based, acknowledging the difficulties for research in this field. Parental feedback has emphasized the importance of an appointment to discuss the death with a neonatologist. This usually occurs some weeks later. Although clinically valuable, post-mortems are not frequently performed11; if results are available, they could be discussed at this time. Parents may wish to address any implications for future pregnancies.

Clinical case: Term female infant, antenatally diagnosed with Trisomy 18, congenital cardiac disease and an exomphalos. The parents found it difficult to accept the diagnosis and initially failed to attend antenatal appointments. Near the time of delivery they accepted neonatal counselling and a care plan was formulated. A baby girl was delivered by Caesarean section (breech presentation) and was admitted to the neonatal unit. She received intravenous fluids (feeds were withheld due to the exomphalos) and analgesia. She gradually deteriorated over 48 h and died on the unit with her mother present.

Comment: Life-sustaining care was withheld as per RCPCH guidance: ‘no chance situation’.
The case for court: parental and staff discord

In the majority of cases, open and regular communication between parents and health professionals leads to agreement regarding the best course of management for the baby. Cases may arise where there is uncertainty of outcome or strong parental wishes in conflict with the physician’s opinion. It is accepted that parents generally have a right to consent to all treatment given to their child. The doctor has a legal and professional duty to administer life-saving treatment, regardless of the parents’ objections and wish to withhold treatment. They are not, however, compelled to deliver treatment that is not in the best interest of the baby.

The Nuffield Council on Bioethics states, ‘the courts have indicated that in defining the boundaries of permissible decisions to withhold treatment, a balancing exercise must be performed’. Continued survival should be balanced against the ‘burden of survival’ and ‘the means of the burden of survival’. They also advise that where there is doubt about a baby’s prognosis, court precedents indicate a strong presumption in favour of providing treatment.

Previous high-profile legal cases which illustrate changes in professional and societal attitudes include the following:

(i) Re v. Arthur 1981: A baby was born with uncomplicated Trisomy 21. The baby received analgesia and water only, dying a few days later. The paediatrician involved was tried for murder but was acquitted. Few clinicians nowadays would accept that a diagnosis of Down’s syndrome justifies withholding nourishment.

(ii) Portsmouth NHS Trust v. Wyatt and Ors (2004): Charlotte Wyatt was born at 26 weeks weighing 458 g. She developed profound brain damage and chronic lung disease. A ‘do not resuscitate order’ was granted through the courts, where her chance of survival for a further year was prognosticated as 5–25%. She is presently 6 years old and living in foster care.


Cultural and religious variations

There is considerable worldwide variation in the resuscitation of preterm infants and neonatal end of life decisions. Active withdrawal of treatment is a common cause of death in the NICU in Europe. The
EPI Cure study reports intensive care was actively withdrawn in 55% of preterm infants who die in the UK,\textsuperscript{17} the Epipage study in France reports this in 45% of cases\textsuperscript{28} and the LFU PP study in the Netherlands reports this in 55% of cases.\textsuperscript{29} The EURONICS multi-centre survey assessed physician’s end of life decisions in the neonatal unit across seven European countries.\textsuperscript{30} Doctors from all countries were found to have ‘set limits to intensive interventions’, including continuation of current treatment without escalation, withholding of emergency treatment and withholding of intensive treatment (the latter with the exception of Italy). Clinicians’ decisions to withdraw ventilation were more variable: The highest rate of physicians in agreement was in the Netherlands, the UK and Sweden, an intermediate rate in France and Germany and lowest in Spain and Italy. France and the Netherlands reported giving drugs with the intention to end life.

In America, common clinical practice includes full resuscitation of infants at 24-week gestation and above and/or \textgreater{}600 g. Palliative care or withdrawal of intensive treatment occurs in cases of extreme prematurity and lethal congenital anomalies. The process to withdraw treatment is more formalised: parents and clinicians agree to ‘reorientate’ care, and a second neonatologist is required to review the case prior to presentation to the hospital’s ethics committee for approval (this step may be a formality but is required by state law).\textsuperscript{31}

Ethnicity and religion is thought to influence the acceptability of withdrawal of intensive treatment. UK parents of White, Afro-Caribbean or Indian subcontinent extraction have been reported to be more likely to agree with withdrawal of care than Black-African or Jewish parents.\textsuperscript{32} Doctors may have strong religious views which affect their decisions to limit therapy. Doctors from Catholic countries, such as Italy, find limitation of treatment more ethically acceptable.\textsuperscript{30} In the Jewish faith active withdrawal of care, e.g. discontinuation of ventilation is forbidden. In clinically stable infants with a poor prognosis, withholding treatment is unacceptable as one should not judge the quality of another’s life. However, if an infant is likely to die then Jewish law states that ‘one must not impede the natural departure of the dying soul’. Doctors can therefore choose not to start new therapies or escalate existing treatment.\textsuperscript{33} Muslims believe the deliberate taking of life is unacceptable and some believe that the ‘premature termination of life through acts of omission’ is also against their teachings.\textsuperscript{34} Spiritual leaders may offer support to parents and advice to clinicians with decision-making.

In developing countries, economic and technological restraints can result in otherwise ‘salvageable’ babies dying without receiving basic neonatal care. Limited resources are directed towards strengthening essential newborn care as opposed to aggressively managing critically unwell extremely preterm infants. The financial burden on the family
may also be taken into account. Infants born in India with lethal congenital malformations or those who are likely to survive with a profound risk of neurodisability may well have treatment withheld or withdrawn. Comfort care offering nutrition, hydration and analgesia is offered instead.

**Growing points and areas timely for developing research**

As the rate of prematurity rises and antenatal diagnosis of life-limiting conditions becomes more common, frameworks for withdrawal of intensive treatment and palliation need to be instigated worldwide. Common pathways will vary depending upon economic, religious and cultural variation but basic legislation needs to be in place to provide guidance to clinicians. In the UK, NICE is currently developing a quality standard for specialist neonatal care. A recent publication by the Neonatal Taskforce for the Department of Health has outlined guidance on developing and coordinating neonatal services and includes outcome measures. The ACT advocates end-of-life planning, and has recently published a neonatal integrated care pathway to support staff in the care of babies with life-limiting or life-threatening conditions. The BAPM is also in the process of forming a framework for clinical practice in peri-natal palliative care. These initiatives will guide and support local unit practice and will provide a standard to audit unit practice against.

Neonatologists are taught to manage medical complications of critically unwell infants. It is often a doctor-in-training who is present when pre-term labour is threatened, initiating the relevant parental conversation and attending the delivery. They therefore require training to address the emotional, spiritual and social needs of families in such circumstances. This should become part of the routine assessment of clinicians in training.

Parents are guided by medical professionals in the treatment of their infant. In the delivery suite, it is extremely difficult for parents to process the proffered medical information and formulate appropriate management plans in conjunction with the attending physician. It is, however, the parents who will have to care for a potentially dependent disabled child over the following years. It has therefore been suggested that prenatal directives could be used as part of routine antenatal care. Written information could be provided about the spectrum of outcomes at different gestations. Counselling would need to be provided in conjunction with this information to ensure comprehension. Parents could then discuss their preferences away from the hospital environment and could choose to provide written documentation detailing their wishes. Advanced directives to refuse treatment are open
to negotiation and, although usually considered legally binding, they are open to review depending upon the progress of their child.

**Conclusion**

The withdrawal of neonatal intensive treatment and provision of palliative care is established practice in the UK and clinical guidance has been published to support clinicians in joint decision-making in the infant’s ‘best interests’. Nevertheless, judicial clarification is sometimes required. The establishment of neonatal outcome databases will further aid decision-making at the extremes of prematurity. There is wide international variation in withdrawal of care and palliation. There is limited evidence as to what constitutes best practice. Most bereavement interventions are ‘compassion led’. Further research, conducted empathically but rigorously, is advocated.

**References**


