Practical guidance for the management of palliative care on neonatal units

1st Edition
February 2014

A Mancini, S Uthaya, C Beardsley,
D Wood and N Modi

RCPCH
Royal College of
Paediatrics and Child Health
Leading the way in Children's Health

Chelsea and Westminster Hospital NHS
NHS Foundation Trust

Acknowledgements

The guidance development group would like to thank:

- Members of the research working group, Dr Katherine Sharpey and Dr Sanjay Valappil
- Ms Rita Ranmal, Dr Munib Haroon and the Clinical Standards Committee of the RCPCH, for their advice and assistance in reviewing this document
- Ria Lane for her role as Project Manager
- The Department of Health for funding this project and Chelsea and Westminster Health Charity for funding the publication of this document

Dedication

This guidance is dedicated to the memory of Dr Sanjay Valappil.

Authors

Ms Alexandra Mancini (Neonatal Matron and Lead Nurse for Neonatal Complex, Palliative and Bereavement Care) BSc (Hons), RGN, Chelsea and Westminster Hospital NHS Foundation Trust

Dr Sabita Uthaya (Consultant Neonatologist and Honorary Senior Lecturer in Neonatal Medicine) MBBS, MD, MRCP, FRCPCH, Chelsea and Westminster Hospital NHS Foundation Trust and Imperial College London

The Revd Dr Christina Beardsley (Head of Multi-Faith Chaplaincy) BA, MA, PhD, Chelsea and Westminster Hospital NHS Foundation Trust

Dr Daniel Wood (Consultant Clinical Psychologist) BSc, DClinPsy, Central and North West London NHS Foundation Trust

Professor Neena Modi (Professor of Neonatal Medicine) MB ChB, MD, FRCP, FRCPCH, FRCPE, Chelsea and Westminster Hospital NHS Foundation Trust and Imperial College London

Stakeholders

Thank you to our stakeholders for taking the time to review and comment on successive versions of this document, which is available for download from their respective websites.

Foreword

The birth of a baby should be a happy event, but approximately one in ten parents will experience the anguish and fear of having their new baby admitted to a neonatal unit. Among these will be infants who require intensive care that is highly complex and technologically challenging and some who have conditions that modern medicine cannot cure. It is in this daunting but highly professional environment that medical science, technology, ethics, faith, hope and emotion intermingle in a way that affects everybody differently at different times. It is not easy for anyone knowing an innocent and loved baby might die.

The goal of all involved in neonatal medicine is to sustain life and restore health, but when this is not possible, babies and their families should still receive the best possible care until the end of life. The life span of infants with terminal conditions may extend from minutes to weeks, months or even years. However long or short, care must always be tailored to individual needs of the infant and family.

I am pleased to introduce this guidance that aims to equip staff working on a neonatal unit with a clear set of principles to underpin the care they provide to babies with life-limiting conditions and support their families through a time of great turmoil. It aims to complement existing resources and has been developed by members of the multidisciplinary neonatal medicine team at Chelsea and Westminster NHS Foundation Trust, in collaboration with the Royal College of Paediatrics and Child Health, and following consultation with a wide group of interested parties. It covers practical aspects of infant care, including pain relief, symptom relief, comfort and dignity, the management of prognostic uncertainties, and the provision of support to families during their baby's illness and afterwards when coming to terms with their loss.

Clinical staff require support as well, to help balance professionalism and empathy through tragic and emotional circumstances, and this is also covered.

I commend this as a valuable resource for all staff working in this difficult, but important and rewarding area.

Professor Sir Bruce Keogh
National Medical Director
NHS England

Contents

Introduction and development of guidance

Professionals working in neonatology have a duty to act in the best interests of the infant. Normally the goal of care is to sustain life and restore health. However, there are circumstances in which treatments that sustain life are not considered to be in the infant's best interest. This document provides practical guidance to equip staff working on a neonatal unit with a clear set of principles to underpin the care they provide to babies and their families, and the support they provide to other staff members, once a decision to withhold or withdraw life-sustaining treatment has been made—it does not cover the process of reaching this decision as several publications address aspects of this subject. The Royal College of Paediatrics and Child Health (RCPCH) guidance *Withholding or Withdrawing Life Sustaining Treatment in Children: A Framework for Practice* (RCPCH, 2nd Edition, 2004) focuses on the decision-making process. The British Association for Perinatal Medicine (BAPM) has also produced national guidance *Palliative Care (Supportive and End-of-Life Care): A Framework for Clinical Practice in Perinatal Medicine* (BAPM, 2010). This sets out the principles of palliative care for infants. Other resources are:

1. *The Management of Babies Born Extremely Preterm at less than 26 weeks of gestation: a Framework for Clinical Practice at the Time of Birth* (BAPM, 2008). This guidance focuses on extremely immature infants.

2. *Critical Care Decisions in Fetal and Neonatal Medicine* (Nuffield Council on Bioethics, 2006). This provides the ethical context for end-of-life decisions.

3. *The Toolkit for High Quality Neonatal Services* (Department of Health, 2009) recommends that professionals receive training in supporting families during the palliative care period and afterwards, and that families receive written information about services and support that is available. Bliss supports these recommendations in their *Baby Charter Standards* (Bliss, 2009)

4. *A Neonatal Pathway for Babies with Palliative Care* (Association for Children's Palliative Care, 2009). This focuses on the principles of palliative care and the decision-making process.

5. *A Care Pathway to Support Extubation within a Children's Palliative Care Framework* (Association for Children's Palliative Care, 2011) addresses the decision-making process and related issues for children of all ages and their families.

6. *Treatment and care towards the end of life: good practice in decision-making* (General Medical Council, 2010) provides generic guidance on end-of-life care including reference to neonates (section 90).

This guidance aims to complement existing resources. The practical aspects of care are covered including pain relief, symptom alleviation, comfort care, management of prognostic uncertainties, and providing support to families and staff. Four out of five neonatal deaths occur after withdrawing or withholding life-sustaining treatment[3, 50, 59, 60]. The life span of these infants may extend from minutes to weeks, months or years. Throughout this period, care must be tailored to individual needs of the infant and family.

Target audience

This guidance is aimed at all clinical professionals involved in the management and care of infants in whom a decision has been made to withhold or withdraw life-sustaining treatment. The guidance has been specifically developed for practice in the United Kingdom but the underpinning principles are relevant globally.

Target population

The target population are all infants for whom a decision has been made to withhold or withdraw life-sustaining treatment. This population is further classified into the five categories defined by the British Association of Perinatal Medicine (2010):

- **Category 1:** An antenatal or postnatal diagnosis of a condition which is not compatible with long term survival, eg bilateral renal agenesis or anencephaly

- **Category 2:** An antenatal or postnatal diagnosis of a condition which carries a high risk of significant morbidity or death, eg severe bilateral hydronephrosis and impaired renal function

- **Category 3:** Babies born at the margins of viability, where intensive care has been deemed inappropriate

- **Category 4:** Postnatal clinical conditions with a high risk of severe impairment of quality of life and when the baby is receiving life support or may at some point require life support, eg severe hypoxic ischemic encephalopathy

- **Category 5:** Postnatal conditions which result in the baby experiencing "unbearable suffering" in the course of their illness or treatment, eg severe necrotising enterocolitis, where palliative care is in the baby's best interest

Funding

This work was funded by the Department of Health as part of a £30 million funding allocation for children's palliative care services in 2010. Printing and publication costs were provided by Chelsea and Westminster Health Charity. The funding bodies had no influence on the content of the guidance.

Development of the guidance

This guidance has been developed following a systematic review of published literature. The *Appraisal of Guidelines for Research and Evaluation II* (AGREE Next Steps Consortium, May 2009) process was followed to synthesise evidence and formulate recommendations.

The guidance development group (GDG) undertook the systematic review and subsequent summary of the evidence. Where there was limited evidence to support recommendations for practice, these were based on the consensus of the GDG. It is acknowledged that there is a paucity of good quality research in this area. The classification of the evidence table can be found in the table "Classification of evidence" on page 6 of this document.

The guidance has been subject to two rounds of stakeholder consultation. Feedback and amendments can be viewed on the RCPCH website. The views of parents and families in the development of the guidance was obtained by a combination of the review of the literature and by involving organisations that provide support to parents and families of the target population in the two rounds of stakeholder consultations.

Methods

The details of the search strategy, classification of the evidence and recommendations can be viewed on the RCPCH website.

Update of the guidance

The guidance document will be updated every 5 years. This will include a literature review and stakeholder consultation.

Introduction and development of guidance

Classification of evidence

Classification of evidence levels	Grades of recommendation
1++ High quality meta-analyses, systematic reviews of RCTs or RCTs with a very low risk of bias	**A** At least one meta-analysis, systematic review or RCT rated as 1++ and directly applicable to the target population, or a body of evidence consisting principally of studies rated as 1+ directly applicable to the target population, and demonstrating overall consistency of results
1+ Well conducted meta-analyses, systematic reviews or RCTs with a low risk of bias	**B** A body of evidence including studies rated as 2++ directly applicable to the target population and demonstrating overall consistency of results, or extrapolated evidence from studies rated as 1++ or 1+
1- Meta-analyses, systematic reviews or RCTs with a high risk of bias	**C** A body of evidence including studies rated as 2+ directly applicable to the target population and demonstrating overall consistency of results or extrapolated evidence from studies rated as 2++
2++ High quality systematic reviews of case control or cohort studies. High quality case control or cohort studies with very low risk of confounding or bias and a moderate probability that the relationship is causal	**D** A body of evidence level 3 or 4 or extrapolated evidence from studies rated as 2+
2+ Well conducted case control or cohort studies with a low risk of confounding or bias and a moderate probability that the relationship is causal	**E** Recommended best practice based on the clinical experience of the guidance development group
2- Case control cohort or cross sectional studies with a high risk of confounding or bias and a significant risk that the relationship is not causal	
3 Non-analytic studies, eg case reports/case series	
4 Expert opinion	

1. How should the infant be managed once a decision has been made to withdraw or withhold life-sustaining treatment?

Summary of evidence

Several papers deal with some or all aspects of care of the infant once a decision is made to institute palliative care. The quality of the papers varies from literature reviews and Delphi-based consensus to expert opinion.

1.1 Discussions with parents

Summary of evidence (Category 4)

Papers highlight the importance of a flexible approach, sensitive to parent views during the actual process of withdrawal and withholding of intensive support[15, 20, 52] (Category 4)[43], (Category 3). Some papers deal with the pathway of palliative care in situations where the fetus is diagnosed with a fetal anomaly and the parents choose to continue with the pregnancy[26, 43, 44] (Category 4).

Recommendations for practice (Grade E)

- Have a face-to-face discussion with both parents in a quiet room away from the neonatal unit. Give them the option of inviting other family members or a close friend to be with them.
- Phrases such as the following may help: "Our aim is to help your baby have a pain-free, peaceful death", "We cannot cure your baby but we will always care for him", "We want to support you through this difficult time".
- Arrange for an interpreter to be present if needed—avoid interpretation by family members or children.
- Ensure that parents have privacy, and adequate time and opportunity to discuss their views and feelings and to ask questions.
- Enable the junior doctor and the nurse caring for the infant to be present during the discussion so that they are aware of the process involved, and gain experience.
- If it is necessary to take samples of tissue before death in order to make a diagnosis, this should be clearly explained to the parents. Consider zygosity testing in the case of same sex twins and triplets. Organisations such as the Multiple Births Foundation (see Appendix 1 for details) can help with zygosity testing.
- Agree a time and location for withdrawal of life-sustaining treatment with the parents.
- Explain what will physically happen to the infant, what to expect practically, and if the length of time until death is uncertain.
- If withdrawal of life-sustaining treatment is likely to lead to immediate death, explain that the infant may gasp and have colour changes to their face and body.
- Ask if the parents would like to be present at the actual time that life-sustaining treatment is withdrawn. Be mindful that they may prefer not to, and also that they may change their mind. Ask the parents whether they would like siblings or family members to be with them.
- Ask if the parents would like their infant to be dressed in a special way, or if they have specific preferences, such as around bathing or anointing.
- Ask if the parents would like to hold their infant.
- Ask if they would like photos to be taken and offer them the opportunity to take handprints and footprints. If parents do not want photos, offer to take some to keep in the medical records in case they decide they would like them at a later date. Ask parents if they wish to keep any items such as blankets, hats or other items that were related to the baby's care.
- If the infant is one of a set of twins, triplets or quads, where possible take a photograph of the babies together with the family. This could be incubators or cots close together if that is the only way to do this if the other infant is very sick.

The guidance

- Ensure the nurse who is allocated to the infant and family does not have another infant to care for. Ask the parents if they would like the nurse to be present behind the screen or in the room with them. If they prefer privacy explain how they can call the nurse and advise that he/she will return intermittently.

- Let parents know that it is possible for their baby to remain with them after death if they wish. If a post mortem examination is to be carried out, it is not advisable to keep the body outside of a cool room or mortuary for longer than 4–6 hours. Parents should be informed that it is possible to see their baby after the body has been taken to the mortuary and following the post mortem. It may be possible for the body to be transferred to a cool room in a children's hospice.

- It may be possible for the family to take the infant home after death until the funeral. Please refer to local guidelines and policies.

- Consider providing written information.

1.2 Pain relief and comfort care

Summary of evidence

The provision of pain relief after life-sustaining care is withdrawn is inconsistent. Lower birth weight infants are less likely to receive analgesic medications[1, 5, 36, 43, 46, 58] (Category 3)[12] (Category 4). Practical guidance on the use of pharmacological agents has been summarised[5] (Category 3). One paper refers to non-invasive delivery of pain relief using intranasal fentanyl[51] (Category 4). Several papers recognise the importance of comfort care although there is very little practical guidance[10, 13] (Category 4). The use of medications to relieve pain may have the unintentional consequence of shortening life, the so-called "doctrine of double effect". However, doctors in some countries have reported the practice of administering medications with the aim of ending life[17, 56] (Category 2)[22, 39, 57], (Category 4). All papers conclude with the recognition of the need for practical guidance on pain relief to infants receiving palliative care[11] (Category 4). Some papers review practice[43] (Category 3) and others provide recommendations based on Delphi consensus[15] (Category 4). Tools to measure pain in infants have many limitations and the recognition of pain and distress is difficult[55]. The oral or buccal route is preferable to the intramuscular and subcutaneous route as this is unreliable in infants, as well as being painful[4] (Category 4).

Recommendations for practice (Grade E)

- Consideration should be given to relief of pain and discomfort for infants receiving palliative care. This includes the type of medication, the dose, route of administration and the likely duration of need. Consideration should also be given to the use of formal tools to assess pain.

- Should the infant have intravenous access in place, this route is preferable in the immediate period after discontinuation of life-sustaining care.

- If an infant is already receiving analgesic medication, this should be continued—if opiates are to be initiated, an initial bolus dose should be given before commencing an infusion so that adequate analgesia is achieved promptly. The dose may be increased or reduced depending on ongoing assessment of distress and development of tolerance—parents should be made aware that opiates while relieving pain and distress also suppress respiratory drive and may hasten death.

- If the intravenous route is not available and adequate analgesia cannot be achieved through oral medication, a subcutaneous infusion may be necessary. Intramuscular medication is never appropriate. For rapid symptom management, buccal medication can be considered, usually in addition to longer acting medication via the enteral route or subcutaneous infusion.

- Non-narcotic analgesia such as paracetamol and oral sucrose may be used for less severe pain or in combination with narcotic analgesics.

- Refer to Appendix 2 for a list of suggested medications and doses.

- Non pharmacological interventions may be used in conjunction with analgesic medications—these include a calm environment with minimal noise and light stimuli, non-nutritive sucking with a pacifier, music, and positioning with arms and legs flexed close to the trunk using a blanket or rolls, and massage.

- Assist the parents to hold their baby.

- Support continued suckling at the breast if the mother wishes.

Mrs A

Mrs A was referred antenatally to the neonatal team at 31 weeks gestation. Her baby had been diagnosed with a skeletal dysplasia with a differential of either Thanatophoric Dysplasia or Osteogenesis Imperfecta. It was uncertain if the baby would survive the pregnancy or the delivery, and, if so, what her life expectancy would be. It was agreed that active resuscitation would not be in the infant's best interest given the lethal condition. Mrs A was concerned that the infant should not experience any pain or distress. She received counselling from the neonatal consultant and matron.

Possible routes for the administration of analgesia were discussed should the infant appear to be in pain from fractures in the case of a diagnosis of osteogenesis imperfecta. It was not considered appropriate to insert an intravenous cannula as this would have involved an uncertain number of painful procedures. The use of buccal morphine was agreed upon and the dose and preparation discussed with the neonatal pharmacist so that this was available after delivery. At birth the baby was born in poor condition, was assessed not to be in pain, and lived only for a few minutes.

Learning point: When a plan is made to withhold intensive care in the antenatal period, consideration should be given to the route and ready availability of any proposed postnatal analgesia.

1.3 Other symptom control

a) Seizures

Summary of evidence (Category 4)

Seizures are a source of distress for the infant, the family and care givers. Seizure medication should be administered using a suitable route[4, 15].

Recommendations for practice (Grade E)

- If an infant is already receiving medications to control seizures before life-sustaining support is withdrawn, this should be continued. If death does not follow the withdrawal of life-sustaining support, ongoing management of seizures should involve a consideration of the type of medication and route of administration.
- Refer to Appendix 2 for medications and doses.

b) Secretions

Summary of evidence (Category 4)

One paper recommends the use of hyoscine and glycopyrrolate to reduce secretions[4].

Recommendations for practice (Grade E)

- Gentle suctioning and medications such as glycopyrrolate or hyoscine may be used to decrease respiratory and salivary secretions.
- Refer to Appendix 2 for medications and doses.

The guidance

1.4 Physiological monitoring

Summary of evidence (Category 4)

All papers that make reference to monitoring of an infant receiving palliative care recommend that invasive and/or electronic monitoring is not appropriate and that intermittent physical assessment should be carried out[15, 20, 52].

Recommendations for practice (Grade E)

- Invasive techniques such as invasive blood pressure monitoring should be discontinued—cardiac and saturation monitors should also be turned off prior to disconnecting mechanical ventilation.
- The infant should be monitored for physical signs that suggest discomfort (crying, whimpering, panting, tachycardia, excessive secretions, dry mucous membranes).
- Blood tests and blood gas measurements should no longer be carried out.
- Once life-sustaining support has been withdrawn, intermittent physical examination with auscultation of the heart rate should be continued by the nurse or doctor caring for the infant.

1.5 Fluids and nutrition

Summary of evidence (Category 4)

Two papers address the continued provision of fluids and nutrition in infants where life-sustaining care is no longer considered in the infant's best interests[14, 48]. Both papers recognise the difficulty doctors and nurses caring for infants with life-limiting conditions have with withholding and withdrawing fluid and nutrition.

It is argued that withdrawal of an endotracheal tube (and consequent respiratory distress) is not morally different from withdrawal of artificial nutrition or hydration (and consequent distress arising from hunger or thirst)[48]. The differences lie in the length of time from the withdrawal of the intervention until death and the method of alleviation.

Baby A

Baby A was born at 28 weeks gestation following antenatal diagnosis of severe hydronephrosis, enlarged bladder, polyhydramnios, and insertion of a vesico-amniotic shunt. He had a stormy postnatal course complicated by intestinal perforation, recurrent bowel obstruction, suprapubic bladder catherisation, periventricular leucomalacia, jejunostomy, bilateral sensorineural hearing loss and chronic lung disease. After several months of feed intolerance, biopsies revealed a diagnosis of congenital bladder and bowel myopathy. At this stage the infant was not on any form of respiratory support but was dependent on parenteral nutrition administered through a central line. Bowel transplant was not considered in his best interests given the presence of severe brain injury.

The parents' wish was to spend time with their baby away from an intensive care unit. All invasive tests and monitoring were stopped. Discussions between the parents and the medical staff resulted in a decision to continue with parenteral nutrition although it was acknowledged that this could prolong life and delay death.

Following discussion with his parents he was transferred, still receiving parenteral nutrition, to a children's hospice after 5 and a half months on a neonatal intensive care unit. This approach allowed the parents time with their infant with the focus of care on his comfort and quality of life. Baby A died two weeks after transfer to the hospice.

Baby B

Baby B was born at 38 weeks gestation to consanguineous parents. She developed functional bowel obstruction and was unable to tolerate even small amounts of enteral feeds. Two laparotomies with stoma formations were performed. Following multiple intestinal biopsies, complete bowel aganglionosis was confirmed. Her parents were strongly opposed to any form of life-sustaining treatment including parenteral nutrition or other intravenous fluid. They were opposed to bowel transplantation given the prolonged wait, substantial risk of liver disease and systemic infection. Baby B had large nasogastric and stoma losses. Her parents expressed the wish to take her home breastfeeding on demand with no lines or tubes and to allow "nature to take its course". Several multidisciplinary meetings followed—after 2 months Baby B was discharged receiving demand breast feeds and intravenous glucose-saline through a percutaneous intravenous catheter. She died two weeks later.

Some of the dilemmas that faced the healthcare team were:

- If the intravenous access had been lost or become infected would the subsequent insertion of surgically placed intravenous catheter be ethically justified? In this instance as the intravenous catheter was already present a decision was made to use it. It was considered inappropriate to insert a surgical catheter for feeding once a decision for palliative care was already made.

- Was it morally and ethically justified to prolong a life with artificial fluids when this was not considered to be in her best interest by her parents? Justification for providing hydration via the intravenous route was the prevention of dehydration resulting from the excessively large fluid losses from the bowel. It could just as easily be argued that symptoms of thirst and hunger could be managed with attention to care of the mucous membranes and skin.

This case highlights the difficulties that face medical and nursing staff in making decisions involving the withholding or withdrawal of artificially provided fluids and nutrition

Learning points: In a situation where an infant is unable to tolerate oral/enteral feeds and where death is not imminent, management of fluids and nutrition requires careful consideration of issues such as route of administration and type of fluid, the location of care, and parental wishes.

Recommendations for practice (Grade E)

- The goal of treatment is comfort, not the provision of nutrition.

- In those infants able to tolerate milk feeds their ongoing provision should be determined by their clinical condition and the cues that the infant demonstrates.

- Oral nutrition should only be withheld if it is felt that providing it will cause pain or discomfort.

- If vomiting is a problem, the volume of enteral feeds should be reduced appropriately.

- It may be appropriate to allow the infant to suckle at the breast if able to do so.

- In those infants in whom the duration between the withdrawal of life-sustaining care and death is expected to be short, it is reasonable to cease all feeds if it is felt feeding could cause distress, and to discontinue intravenous hydration and nutrition.

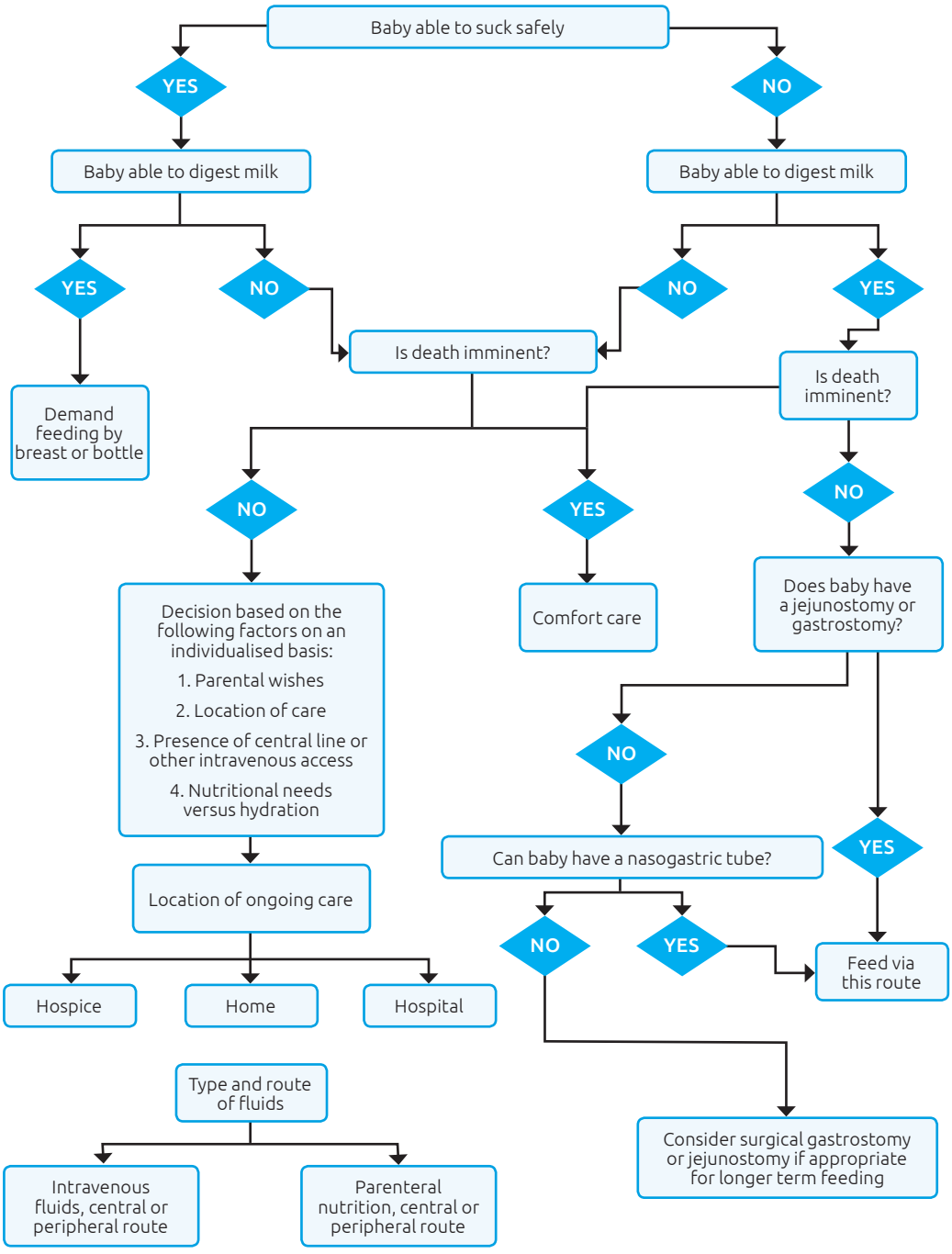
- If death does not follow the withdrawal of life-sustaining care, or if palliative care is instituted in an infant where the provision of hydration and nutrition is the sole intervention maintaining life, then considering stopping this is appropriate only if to do so will not result in hunger or distress to the infant. Any such decision should involve discussion with the parents.

- Any decision to continue to provide intravenous nutrition and hydration should be taken in the light of the pain and discomfort to the infant of continuing to provide fluid and nutrition (eg need for central or peripheral venous access).

The guidance

- If the infant is discharged home or to a hospice for palliative care, arrangements to continue or discontinue medically provided fluids and nutrition will need to be made in advance and the parents supported accordingly.
- Gastrostomy, nasogastric and jejunostomy feeding will require parent training and professional community support.
- The benefits of surgery to allow feeding either via the intravenous route or via the enteral route must be balanced against the burden of the intervention and the prolongation of death.

Suggested algorithm for the management of fluid and nutritional intakes



1.6 Ventilation and oxygen

Summary of evidence

Several papers address the withdrawal of mechanical ventilation[5, 43] (Category 3)[11, 44], (Category 4)[19], (Category 2), agreeing that invasive ventilation constitutes life-sustaining support.

Some papers address the use of oxygen to relieve symptoms or air hunger but conclude that opiate analgesia rather than oxygen may be more effective at relieving such distress[11, 15] (Category 4).

Recommendations for practice (Grade E)

- Explain exactly to the parents what will happen, when it will happen and which member of staff will be present.
- Explain that death may not be immediate and that the infant may survive for a prolonged period.
- Explain how the infant will be cared for.
- Decide in advance which member of staff will be responsible for the actual removal of the endotracheal tube and turning the ventilator off.
- Aspirate the nasogastric tube—consider not feeding the infant just prior to extubation.
- Turn off the alarms of the ventilator and monitors prior to disconnecting these.
- Suction the endotracheal tube before removal.
- Give the parents the choice of being present and holding their infant
- Withdrawal of less invasive forms or respiratory support such as nasal continuous positive airway pressure and nasal cannula oxygen may be appropriate if a baby is dying and continued provision of respiratory support only serves to delay death.

1.7 Location of care

Summary of evidence

There are advantages and disadvantages of different locations[16, 18, 27] (Category 4)[24], (Category 3). It may not be practicable to arrange to move the infant to a different location.

Recommendations for practice (Grade E)

- The principles of palliative care should be consistently applied regardless of location.
- The best available space with privacy and comfort for parents and family should be used.
- Discuss with parents if they prefer to stay in the neonatal unit with a screen for privacy or move to a side room if available.
- If the mother is receiving care herself (for example after a caesarean section) consider providing palliative care on the postnatal wards in a private area that does not compromise her own care and provide nursing support for the infant.
- Consider transfer to a hospice, especially if the duration between the withdrawal of life-sustaining treatment and death is expected to be days rather than hours—ensure this option is available before discussing it with the parents.
- When an infant is transferred to a hospice supported by a palliative care team, it is recommended that there is a designated senior neonatal doctor with whom the palliative care team can liaise after discharge. This is particularly important should there be a change in the infant's condition after discharge.
- Consider the possibility of transfer home or to a hospital closer to home, prior to extubation. The family may have established relationships with staff at the local hospital or may wish to have family nearby. This can only be done if there is sufficient support available at the chosen location to support extubation and provide ongoing care.
- Liaise with community palliative care services and the transport team to ensure services and support can be provided before discussing options with families.
- Tailor care to the individual needs of the infant and the family, but be realistic.
- If a decision to institute palliative care has been made in the antenatal period consider offering parents the opportunity to visit a hospice.
- Throughout this process it is important to communicate regularly current information with other specialties that may be hospital or community based. This could include GPs, health visitors, community nursing teams and maternity services involved in the care of the infant and who can support the family.

The guidance

Baby C

Baby C was born at term following an emergency caesarean section under general anaesthetic after an antepartum haemorrhage secondary to velamentous insertion of the cord and vasa praevia. The baby received prolonged resuscitation, suffered significant hypoxic ischaemic encephalopathy and withdrawal of life support treatment was considered appropriate. The father wished to wait for his wife to recover from the general anaesthetic before this took place. The mother who was unwell herself was unable to spend time with her baby on the neonatal unit. The baby was extubated on the neonatal unit and transferred to a side room on the postnatal ward where a neonatal nurse continued to provide one to one care. Seizures were controlled on the postnatal ward—medications were administered by umbilical catheter. The mother wished to suckle her baby, and was supported to do so. Their daughter lived for two days—during this time the parents had uninterrupted time with her. After the baby died a cooling mattress was used so that she was able to remain in their room on the postnatal ward for several hours.

Learning point: Traditionally palliative care is rarely provided on a postnatal ward, when an infant requires seizure management. In this case it was possible to provide this with support from a neonatal nurse. A location was chosen that was out of earshot of healthy crying babies, something the couple mentioned when seen subsequently for bereavement counselling. The parents cherished the time they had spent with their daughter both during life and after.

Baby D

Baby D was one of monochorionic diamniotic twins born at 28 weeks of gestation with oesophageal atresia and tracheo-oesophageal fistula. She spent 6 months on the neonatal unit long after her twin had been discharged home. Visiting restrictions during the bronchiolitis season meant that her twin was unable to visit the unit after her discharge. Baby D had several operations. After an operation to close the gap in the oesophagus she sustained severe brain injury and palliative care was instituted. It was anticipated that she might live for days or weeks. The parents' wish was to take her home and spend time as a family with their twins. Before this took place the twins were able to spend time together on the neonatal unit in a parents' room and have photos and videos taken together. With support from the palliative care team and the neonatal unit nursing staff, the baby was transferred home while receiving some jejunostomy feeds. An open door policy was instituted, with a parents' room on the unit kept free for the family should respite be required. Baby D lived for a week after discharge. During this period the neonatal consultant and the palliative care team maintained contact with the parents. With help from the Multiple Births Foundation, zygosity testing with buccal smears was carried out on both twins at home as there was a suspicion of a mitochondrial disorder. As this would have had implications for the well twin confirmation of zygosity was carried out. After death the neonatal consultant visited the family at home to discuss post-mortem examination and seek consent.

Learning points: In a situation where one of twins is receiving palliative care, consideration must be given to allowing the family time together with both infants. Consider zygosity testing for all same sex dichorionic twins. Not knowing if twins were identical can be a great regret for the surviving twin or triplets and parents later on.

2. How should conflicts about end-of-life decisions on the neonatal unit be resolved in practice?

Summary of evidence

In making a decision to change the focus of care to palliation there may be occasions when there is a difference of opinion, between the infant's parents and the clinical team, among the members of the clinical team[25, 37] or between the parents themselves.

RCPCH guidance on withdrawing and withholding life-sustaining treatment advises that unanimity between the members of the healthcare team is not essential and the ultimate responsibility for the decision lies with the senior clinician in charge. Verhagen et al[57] studied the frequency and background of end-of-life decision-making in the Netherlands. Conflicts within the team arose in 4% of cases and between parents and health care professionals in 12%. All conflicts were resolved by reaching consensus that involved further meetings, carrying out more investigations and seeking a second opinion (Category 3). Resolution of disagreements by negotiation, conciliation and compromise, is also referred to by Larcher et al[30] (Category 4).

Where consensus between parents and staff cannot be reached, Nelson and Shapiro[45] consider the role of a clinical ethics committee (Category 4). They suggest that the primary role of the committee should be to provide a forum for open discussion. Consensus may be reached but should not be the goal. They further suggest that the discussions, but not the advice, of the committee should be admissible in judicial proceedings. A Swiss survey of practice found that in no instance was a decision made to withhold or withdraw intensive support without parental agreement[5] (Category 3).

2.1 Conflicts between parents and staff

Recommendations for practice (Grade E)

These recommendations are based on a summary of steps reported by clinicians in interviews[57] expert opinion on the role of clinical ethics committees, and consensus within the GDG.

- Allow parents time to consider the decision and arrange for the senior clinician to see them again after the initial meeting in which the decision to institute palliative care was reached.
- Reassure them that withdrawal of life-sustaining treatment does not mean that care of their infant will be withdrawn but rather that there will be a shift in the focus of care. Staff should not appear judgmental should a parent indicate a wish to continue life-sustaining support.
- If relevant, explain that life support technology is not in itself a curative treatment and does not change the baby's underlying condition.
- Explore the reasons behind the parents' views of the situation.
- Suggest parents might find it helpful to discuss their feelings with family, friends or spiritual/religious figures—offer access to hospital religious representatives if appropriate.
- Offer parents a second opinion either with another senior clinician within the team or outside the hospital of care.
- Consider approaching a clinical ethics committee if access to one exists or medical mediation services if appropriate.
- While awaiting the outcome of these actions, provide parental reassurance that the care of their infant will continue unchanged.

Baby E

Baby E was born at 24 weeks gestation and suffered many of the complications of prematurity including severe bilateral periventricular haemorrhage, chronic lung disease and surgery for necrotising enterocolitis. Acute renal failure ensued and the baby developed a full thickness dehiscence of the abdominal surgical wound and external extravasation of bowel. Baby E's mother was single, unsupported and of Muslim faith. She felt unable to agree to the recommendation that life-sustaining support be withdrawn. The focus of care for this baby was redirected to palliation while continuing to receive life-sustaining treatment. Comfort care and analgesia were provided and interventions minimised—a major consideration for staff was Baby E's mother. She received support from the hospital Imam, clinical psychologist and her sister. Staff also required support from the clinical psychologist in dealing with their distress. The mother was well aware that her baby appeared to be distressed and in pain and acknowledged this. In their efforts to bring the mother around to agreeing to withdrawal of intensive support, staff caring for the baby admitted to reiterating this message at every opportunity along with reassurances that pain relief was being escalated. The baby died still receiving mechanical ventilation two weeks after care was redirected to palliation.

When seen for bereavement counselling several weeks later, the mother of Baby E stated that she perceived the staff's focus on pain relief for the baby as being judgmental of her decision not to withdraw life-sustaining treatment. She stated that as a mother she was acutely aware of her baby's distress and her inability to agree to withdrawal of intensive support should not have been perceived as her being indifferent to the pain her baby was in.

Learning point: This case illustrates the emotional distress that staff caring for sick babies may feel. Staff should be encouraged to express this to the consultant in charge of the baby, as an outlet for their feelings. Staff must be careful not to let their feelings of distress, and hence a focus on pain and analgesia for the baby dominate their conversations with the family.

2.2 Conflicts among members of staff

Recommendations for practice (Grade E)

- All members of staff whatever their level of seniority should be included in discussions about the ongoing care of the infant and in decisions about appropriateness of continuing life-sustaining support—the weight of the opinion of each member of the clinical team will depend on their experience but the ultimate decision rests with the senior clinician in charge.
- Regular, scheduled and well attended unit meetings, psychosocial meetings and multidisciplinary case discussions promote team cohesiveness, and healthy team functioning, and are key means of reducing conflict between staff, and reducing the potential for escalation.
- An external facilitator may be helpful where there is significant conflict.
- Neonatal units should have access to a clinical psychologist and staff should be aware of other sources of support (Appendix 1).
- Reflective practice sessions facilitated by a trained member of staff can be helpful both before and after a decision to institute palliative care has been made—staff should be offered debriefing after the death.
- Chaplaincy/multi-faith chaplaincy/spiritual care team members can provide support for staff especially when strong beliefs are a factor.

3. What support should be offered to parents and families once palliative care is instituted for an infant, and what bereavement support should be provided?

3.1 Religious, pastoral and spiritual support

Summary of evidence (Category 4)

The spiritual care of families is a shared responsibility of the multidisciplinary team. In many settings chaplains are an integral part of the palliative care team. When available, parents should be informed of this means of additional support[8].

Medical and nursing staff can support families by their sensitivity to spiritual matters and by facilitating referrals to chaplaincy[34] or the family's preferred religious leader[11]. Support services, including chaplaincy, are sometimes under-utilised and it is recommended that staff are made aware of local provision[33]. Recording families' religious affiliation is often overlooked[47] and the documentation of emotional or social support is frequently lacking[1].

Support provided by chaplains and other religious leaders is described as being helpful for families[1, 9, 11]. Rites can include listening, prayer, blessing or anointing with oil, baptism and other initiation rites, funerals and mourning rituals, and advice on cultural and religious practices such as fasting[35].

Recommendations for practice (Grade E)

Consultations from a dedicated palliative care team can support the neonatal team in providing optimum care for the baby and the family, and increase the support provided by chaplains[9, 23, 24, 33].

- The family's religion should be documented when taking the admission history.
- Staff should assess the spiritual and religious needs of the family and if appropriate, refer to the chaplaincy/multi-faith chaplaincy/spiritual care team or ask if the family would like to have their own religious or spiritual representative contacted.
- Staff should be aware that each family is individual and will have different beliefs, and cultural and religious backgrounds.
- Be respectful of the family's religious beliefs and rituals—if you are unsure of rituals or correct procedures, ask the family.
- Be mindful that the mother and the father may have different religious or cultural beliefs.
- While reasonable to consider offering families who describe themselves as 'not religious' or 'non-practicing' the offer of a prayer or a blessing, their views should be respected.

Baby E

(Reference "Baby E" on page 16)

Learning point: Most UK hospitals have a multi-faith team able to provide support to parents and families of infants on a neonatal unit. The mother of Baby E was offered daily religious and cultural support by the hospital's Imam who was able to advise her that in the absence of curative treatment withdrawal of intensive support was not against the principles of the religion. Although the mother felt unable to agree to the clinical recommendation that intensive support for her baby should be withdrawn, her decision was fully informed.

3.2 Psychological and emotional support

Summary of evidence (Category 3)

Several papers describe the importance of supporting parents through the process of making critical care decisions that involve their baby. This may be provided by a wide variety of professionals[1, 44, 61, 62]. There is agreement that parents and families value opportunity to spend as much time as they would like with their infant in privacy, and be given every opportunity to create memories together as a family[2, 11, 20, 22, 30, 31, 33, 40, 43]. However, it is important to note that the literature in this context is dominated by studies that focus on bereavement support following death. Professionals benefit from training in supporting families[28].

In relation to support following death, the literature suggests a follow up bereavement appointment should be scheduled within two months of the infant's death with a neonatologist known to the family, and a nurse who cared for the baby and has an established relationship with the family[15, 30, 39]. A review of the literature of bereavement interventions after a neonatal death concluded that there is insufficient evidence available and therefore there is the need for further research to be undertaken in this area to determine the effectiveness of bereavement interventions[23, 49] (Category 2++).

The literature regarding grief has viewed the experience as a journey whereby individuals who have experienced loss pass through a series of stages leading to acceptance of the loss, through to re-engagement with the world[63]. More recent papers have described the experience more as an oscillation between 'loss orientated' processes (such as experience of grief and avoidance of change) and 'restoration orientated' processes (such as distraction from grief and the development of new identities and re-engagement in relationships)[53]. While the former model suggests that a more directive form of support might be useful, ie to help the bereaved person move through the various stages, the latter model suggests that simply providing a space for the individual to explore and reflect on the process they are engaged in, in a containing environment, would be more helpful.

Evidence to support the provision of psychological interventions in bereavement has been equivocal and suggests that not everyone who has experienced the death of a loved one benefits from bereavement counselling[54]. However, there is evidence that those who have experienced bereavement in sudden, traumatic and stressful circumstances are most at risk of developing complicated grief reactions and papers suggest that counsellors should focus their efforts on this sub-group of the bereaved. Parents of infants who die on a neonatal unit could be described as experiencing their bereavement in such circumstances.

Research on the efficacy of bereavement interventions in neonatal care is similarly limited—however, there is evidence that parents value support and find it helpful[23]. Harvey et al (2008) point out that although the evidence for efficacy may be limited there are clear compassionate and ethical reasons why such support should be offered.

Very little information exists in the literature on lactation suppression for women who are breastfeeding at the time palliative care is instituted. Practical support for women previously breastfeeding or expressing whose infant has died or in whom death is imminent has been summarized by Moore and Catlin[41]. A protocol has been proposed which relies on engorgement (but not painful engorgement) as a stimulus for the suppression of lactation (Category 4). Suppression of lactation could also include the use of medications such as cabergoline, a dopamine D2 receptor agonist that inhibits prolactin secretion, milk expression without emptying the breast completely, and milk donation.

Recommendations for practice (Grade: E)

- The primary providers of immediate emotional and psychological support to families on the neonatal unit are frontline nursing and medical staff—they should be empowered through awareness of the support available, to offer appropriate choices to families tailored to their needs.
- Parents should be informed of the availability of support, but it must be parents' decisions as to whether they take up the offer. There is some evidence that the most benefit is realised by those who actively request support.
- Staff should be aware that families might show their distress in different ways—they may be tearful, withdrawn, short-tempered or angry.
- Some families may be adept at communicating the full extent of their distress whereas other may find their capacity to communicate diminished in times of stress.
- Families' needs for support vary. Some may wish frequent appointments immediately following the death of an infant—others may wish for shorter, more specific support, such as how best to support a sibling.
- Parents with a surviving twin/triplet require specific bereavement support as they may be caring for another sick baby on the unit or even a healthy child at home.
- Support may be provided by a range of professionals, such as a clinical psychologist, child psychotherapist, or counselling psychologist—what is important is that the professional providing support is knowledgeable and experienced in working with parents who have had an infant on a neonatal unit and of specific issues regarding multiple births, especially where there is a surviving co-sibling.
- Information on any financial support available to assist with the funeral and time taken out of work should be provided.
- Inform families of the name of the staff member who will contact them and when, and provide written information about this and how to access ongoing bereavement support, Provide further support where necessary if parents experience secondary losses, such as a change in their relationship.
- Support should be offered by the neonatal team for as long as required and when appropriate refer to other support services.
- For other organisations that provide support for parents refer to Appendix 1.
- Inform mothers of the options available for lactation suppression should this be required.

4. What is good practice in relation to seeking consent for post mortem examination and organ donation in infants?

Summary of evidence (Category 4)

The best time to broach the issue of post mortem is after the infant's death[15] (Category 4). The reasons parents report declining consent for post mortem examination are fear of disfigurement, and that they have no questions to be answered[38]. Early liaison with a transplant coordinator, to establish feasibility, is necessary if organ donation is being considered[20, 15] (Category 4).

Recommendations for practice (Grade E)

- If parents raise the issue of post mortem examination themselves, discussion before the infant's death is acceptable.
- A post mortem examination should be offered to all parents of infants that die even if the cause of death appears obvious. This may identify unsuspected problems. The person taking consent should be trained to do this and the parents provided with written information[7].
- If the cause of death is unclear, discuss the need for a post mortem examination with the relevant authority (Coroner/Procurator Fiscal) including deaths at home or the hospice.
- Some parents may wish to donate their infant's organs—it is important to establish if this is possible and if not, then to explain why this is the case. Donation of heart valves is usually considered for infants whose death is expected within a specific time period. This is possible only if the infant is above 37 weeks gestation with a weight of 2.5 kg and above and the valves must be harvested within 48 hours of death. Currently the only Heart Valve Bank retrieving heart valves from neonates is the Oxford Heart valve Bank. The United Kingdom Hospital Policy for Organ and Tissue Donation (UK Transplant, April 2003) refers to organ donation from anencephalic infants in the event that a suitably matched recipient is waiting. If heart donation, which is the only suitable organ for donation from anencephalic infants is not possible the option of heart valve donation may be discussed with the parents. This type of donation is rare in the UK and further guidance is awaited.

Case studies

Parents may have clear views that they would like to donate organs post mortem. It is important that these views are discussed and information provided. Currently there is no national guidance.

Postnatal decision
The parents of a term infant with hypoxic-ischaemic encephalopathy expressed their wish before intensive support was withdrawn to donate their infant's organs if this was possible. Heart valves were harvested after death in the hospital mortuary after liaison with the national transplant coordinator

Antenatal
An infant born at 31 weeks gestation with Thanatotrophic Dysplasia was unsuitable for donation of heart valves although the parents expressed a wish for this to take place during the antenatal period. This was because the infant was preterm and the birth weight was less than 2.5 kg.

Learning points: Knowledge of transplant feasibility can facilitate parents' wishes to donate their dying baby's organs.

5. What support is needed by staff to help them manage an infant receiving palliative care?

Summary of evidence

Counselling, debriefing, and emotional support of staff are highlighted in guidance published on neonatal palliative care[15, 20, 65] (Category 2). Staff may experience moral distress if they feel unable to advocate for a patient's interests because of institutional constraints or if they are not in accord with parent decisions[15] (Category 4).

Recommendations for practice (Grade E)

- Neonatal staff should have access to a clinical psychologist and providers of spiritual support.
- Staff should receive training in the principles of palliative care and sensitive communication with parents.
- All members of staff whatever their level of seniority should be included in discussions about the ongoing care of the infant, and in decisions about the appropriateness of continuing intensive support.
- Staff should be offered debriefing after a death. This might take the form of focused reflective practice sessions facilitated by a trained member of staff or external facilitator. This is distinct from a more traditional medical debrief in that it allows a space for team members to develop a shared narrative of events, appreciate practice that has gone well, and consider alternative ways that families might be supported.
- All staff should be allowed and supported to care for families who have a baby receiving palliative care, rather than allowing the expertise to be concentrated in a small group of workers. In this way all staff can appreciate the experience of the families as well as the needs and experience of those that care for them.
- There are papers that suggest that caring for babies at the end-of-life should be voluntary for staff[15] and if staff members feel unable to care for such infants they should be assigned to other duties. The General Medical Council (Section 'Personal Beliefs and Medical Practice' under Guidance on Good Practice) states that it is not acceptable to opt out of treating a particular patient or groups of patients because of personal beliefs or views about them. The Nursing and Midwifery Council's Code of Conduct in the UK states that nurses should not discriminate in any way against those for whom they provide care. The consensus within the GDG is that members of staff who express their reluctance to care for infants at the end-of-life should receive support and training to enable them to fulfil this role.

References

1. Abe N, Catlin A, Mihara D 2001 *End of life in the NICU. A study of ventilator withdrawal.* MCN Am J Matern Child Nurs 26:141–6

2. Armentrout D 2009 *Living with grief following removal of infant life support: parents' perspectives.* Critical Care Nursing Clinics of North America 21(2):253–65

3. Barton L, Hodgman J E 2005 *The contribution of withholding or withdrawing care to newborn mortality.* Pediatrics 116:1487–91

4. Bell S G 2004 *The pharmacology of palliative care.* [Review]. Neonatal Network 23(6):61–4,

5. Berner M E, Rimensberger P C, Huppi P S, Pfister R E 2006 *National ethical directives and practical aspects of forgoing life-sustaining treatment in newborn infants in a Swiss intensive care unit.* Swiss Medical Weekly 136(37–8):597–602

6. Bhatia J 2006 *Palliative care in the fetus and newborn.* [Review]. Journal of Perinatology 26 Suppl 1:S24–6, discussion S31–3

7. Brodlie M, Laing I A, Keeling J W, McKenzie K J 2002 *Ten years of neonatal autopsies in tertiary referral centre: retrospective study.* BMJ 324:761–3

8. Calhoun B C, Hoeldtke N J, Hinson R M, Judge K M 1997 *Perinatal hospice: should all centers have this service?* Neonatal Network—Journal of Neonatal Nursing 16(6):101–2

9. Calhoun B C, Napolitano P, Terry M, Bussey C, Hoeldtke N J 2003 *Perinatal hospice. Comprehensive care for the family of the fetus with a lethal condition.* Journal of Reproductive Medicine 48(5):343–8

10. Carter B S 2004 *Providing palliative care for newborns.* Pediatric Annals 33(11):770–7

11. Carter B S, Bhatia J 2001 *Comfort/ palliative care guidelines for neonatal practice: development and implementation in an academic medical center.* Journal of Perinatology 21(5):279–83, Aug

12. Carter B S, Howenstein M, Gilmer M J, Throop P, France D, Whitlock J A 2004 *Circumstances surrounding the deaths of hospitalized children: opportunities for pediatric palliative care.* Pediatrics 114(3):e361–6

13. Carter B S, Hubble C, Weise K L 2006 *Palliative Medicine in Neonatal and Pediatric Intensive Care.* Child and Adolescent Psychiatric Clinics of North America 15(3):759–77

14. Carter B S, Leuthner S R 2003 *The Ethics of Withholding/Withdrawing Nutrition in the Newborn.* Seminars in Perinatology 27(6):480–7

15. Catlin A, Carter B S 2001 *Creation of a neonatal end-of-life palliative-care protocol.* Journal of Clinical Ethics 12(3):316–8

16. Cavaliere T 2007 *Should neonatal palliative care take place at home, rather than the hospital?* Pro. MCN, American Journal of Maternal Child Nursing 32(5):270

17. Cooke R W 2004 *Should euthanasia be legal? An international survey of neonatal intensive care units staff.* Archives of Disease in Childhood Fetal & Neonatal Edition 89(1):F3

18. Craig F, Goldman A 2003 *Home management of the dying NICU patient.* [Review]. Seminars in Neonatology 8(2):177–83

19. Cuttini M, Nadai M, Kaminski M, Hansen G, de Leeuw R, Lenoir S, Persson J, Rebagliato M, Reid M, de Vonderweid U, Lenard H G, Orzalesi M, Saracci R 2000 *End-of-life decisions in neonatal intensive care: physicians' self-reported practices in seven European countries.* EURONIC Study Group. Lancet 355(9221):2112–8

20. Gale G, Brooks A 2006 *Implementing a palliative care program in a newborn intensive care unit.* Advances in Neonatal Care 6(1):37–53

21. Glicken A D, Merenstein G B 2002 *A neonatal end-of-life palliative protocol—an evolving new standard of care?* Neonatal Network 21(4):35–6

22. Haas F *Bereavement care: seeing the body.* Nursing Standard. 2003 Mar 26–Apr 1, 17(28):33–7

23. Harvey S, Snowdon C, Elbourne D 2008 *Effectiveness of bereavement interventions in neonatal intensive care: a review of the evidence.* [Review] Seminars in Fetal & Neonatal Medicine 13(5):341–56

24. Hawdon J M, Williams S, Weindling A M 1994 *Withdrawal of neonatal Intensive care in the home.* Archives of Disease in Childhood 71(2):F142–4

25. Hazebroek F W, Smeets R M, Bos A P, Ouwens C, Tibboel D, Molenaar J C 1996 *Staff attitudes towards continuation of life-support in newborns with major congenital anomalies.* European Journal of Pediatrics 155(9):783–6

26. Hoeldtke N J, Calhoun B C 2001 *Perinatal hospice.* [Review]. American Journal of Obstetrics & Gynecology 185(3):525–9

27. Howe T H 2007 *Should neonatal palliative care take place at home, rather than the hospital?* Con. MCN, American Journal of Maternal Child Nursing 32(5):271

28. Kain V J 2006 *Palliative care delivery in the NICU: what barriers do neonatal nurses face?* [Review]. Neonatal Network 25(6):387–92

29. Laing I A, Piyasena C 2010 *Analgesics, sedatives and neuromuscular blockers as part of end-of-life decisions in Dutch NICUs.* Archives of Disease in Childhood Fetal & Neonatal Edition 95(5):F385

30. Larcher V, Hird M F 2002 *Withholding and withdrawing neonatal intensive care.* Current Paediatrics 12(6) (pp470–5)

31. Leuthner S R 2004 *Fetal palliative care.* Clinics in Perinatology 31(3) (pp649–65)

32. Leuthner S R 2004 *Palliative care of the infant with lethal anomalies.* [Review] [26 refs]. Pediatric Clinics of North America 51(3):747–59, xi

33. Leuthner S R, Boldt A M, Kirby R S 2004 *Where infants die: examination of place of death and hospice/home health care options in the state of Wisconsin.* Journal of Palliative Medicine 7(2):269–77

34. Leuthner S R, Pierucci R 2001 *Experience with neonatal palliative care consultation at the Medical College of Wisconsin*—Children's Hospital of Wisconsin. Journal of Palliative Medicine 4(1):39–47

35. Lundqvist A, Nilstun T, Dykes A K. *Neonatal end-of-life care in Sweden.* Nursing Critical Care. 2003, 8(5):197–202

36. Matthews A L, O'Conner-Von S 2008 *Administration of comfort medication at end of life in neonates: effects of weight.* Neonatal Network 27(4):223–7

37. McHaffie H E, Fowlie P W 1998 *Withdrawing and withholding treatment: comments on new guidelines.* Archives of Disease in Childhood 79(1):1–2

38. McHaffie H E, Fowlie P W, Hume R, Laing I A, Lloyd D J, Lyon A J 2001 *Consent to autopsy for neonates.* Archives of Disease in Childhood Fetal Neonatal Ed 85:F4–7

39. McHaffie H E, Laing I A, Lloyd D J 2001 *Follow up care of bereaved parents after treatment withdrawal from newborns.* Archives of Disease in Childhood Fetal & Neonatal Edition 84(2):F125–8

40. McHaffie H E, Lyon A J, Fowlie P W 2001 *Lingering death after treatment withdrawal in the neonatal intensive care unit.* Archives of Disease in Childhood Fetal & Neonatal Edition 85(1):F8–12

41. Moore D B, Catlin A 2003 *Lactation suppression: forgotten aspect of care for the mother of a dying child.* [Review]. Pediatric Nursing 29(5):383–4

42. Moratti S 2011 *Ethical and legal acceptability of the use of neuromuscular blockers (NMBs) in connection with abstention decisions in Dutch NICUs: interviews with neonatologists.* Journal of Medical Ethics 37(1):29–33

43. Moro T, Kavanaugh K, Okuno-Jones S, Vankleef J A 1920 *Neonatal end-of-life care: a review of the research literature.* [Review]. Journal of Perinatal & Neonatal Nursing 262–73

44. Munson D 2007 *Withdrawal of mechanical ventilation in pediatric and neonatal intensive care units.* [Review]. Pediatric Clinics of North America 54(5):773–85, xii

45. Nelson R M, Shapiro R S 1995 *The role of an ethics committee in resolving conflict in the neonatal intensive care unit.* Journal of Law, Medicine & Ethics 23(1):27–32

46. Partridge J C, Wall S N 1997 *Analgesia for dying infants whose life support is withdrawn or withheld.* Pediatrics 99(1) (pp76–9)

47. Pierucci R L, Kirby R S, Leuthner S R 2001 *End-of-life care for neonates and infants: The experience and effects of a palliative care consultation service.* Pediatrics 108(3): 653–60

References

48. Porta N, Frader J 2007 *Withholding hydration and nutrition in newborns*. Theoretical Medicine & Bioethics 28(5):443–51

49. Romesberg T L 2007 *Building a case for neonatal palliative care.* [Review]. Neonatal Network 26(2):111–5

50. Roy R, Aladangady N, Costeloe K, Larcher V 2004 *Decision making and modes of death in a tertiary neonatal unit.* Arch Dis Child Fetal Neonatal Ed 89:F527–30

51. Stenekes S, Harlos M, Lambert D, Hohl C, Chochinov H, Ens C 2011 *Use of intranasal fentanyl in palliative care of newborns and infants (416-C).* Journal of Pain and Symptom Management Conference: Annual Assembly of American Academy of Hospice and Palliative Medicine and Hospice and Palliative Nurses Association Vancouver, BC Canada. Conference proceedings.

52. Stringer M, Shaw V D, Savani R C 2004 *Comfort care of neonates at the end of life.* [Review]. Neonatal Network 23(5):41–6

53. Stroebe M, Schut H 1999 *The dual process model of coping with bereavement: rationale and description.* Death Stud 23:197–224

54. Stroebe W, Schut H, Stroebe M S 2005 *Grief work, disclosure and counseling: do they help the bereaved?* Clin Psychol Rev 25:395–414

55. Thewissen L, Allegaert K 2011 *Analgosedation in neonates: do we still need additional tools after 30 years of clinical research?* Arch Dis Child Educ Pract Ed 96:112–8

56. van der Heide A, van der Maas P J, van der Wal G, Kollée L A, de Leeuw R 2000 *Using potentially life-shortening drugs in neonates and infants.* Critical Care Medicine 28(7):2595–9

57. Verhagen A A, de Vos M, Dorscheidt J H, Engels B, Hubben J H, Sauer P J 2009 *Conflicts about end-of-life decisions in NICUs in the Netherlands.* Pediatrics 124(1):e112–9

58. Verhagen A A, Dorscheidt J H, Engels B, Hubben J H, Sauer P J 2009 *Analgesics, sedatives and neuromuscular blockers as part of end-of-life decisions in Dutch NICUs.* Archives of Disease in Childhood Fetal & Neonatal Edition 94(6):F434–8

59. Verhagen A A, Dorscheidt J H, Engels B, Hubben J H, Sauer P J 2009 *End-of-life decisions in Dutch neonatal intensive care units.* Arch Pediatr Adolesc Med 163:895–901

60. Wilkinson D J, Fitzsimons J J, Dargaville P A, Campbell N T, Loughnan P M, McDougall P N, Mills J F 2006 *Death in the neonatal intensive care unit: changing patterns of end of life care over two decades.* Arch Dis Child Fetal Neonatal Ed 91:F268–71

61. Williams C, Munson D, Zupancic J, Kirpalani H 2008 *Supporting bereaved parents: practical steps in providing compassionate perinatal and neonatal end-of-life care.* A North American perspective. Seminars In Fetal & Neonatal Medicine 13(5):335–40

62. Williamson A, Devereux C and Shirtliffe J 2009 *Development of a care pathway for babies being discharged from a level 3 neonatal intensive care unit to a community setting for end-of-life care.* Journal of Neonatal Nursing, 15(5):164–8

63. Worden J W 1983 *Grief Counselling and Grief Therapy.* Tavistock London

64. Wright V, Prasun M A, Hilgenberg C 2011 *Why is end-of-life care delivery sporadic?: A quantitative look at the barriers to and facilitators of providing end-of-life care in the neonatal intensive care unit.* Advances in Neonatal Care 11(1):29–36

65. Yam BM, Rossiter J C, Cheung K Y 2001 *Caring for dying infants: experiences of neonatal intensive care nurses in Hong Kong.* Journal of Clinical Nursing 10(5):651–9

Appendices

Appendix 1

Contact details for support groups

Appendix 2

Medications and dosages

Appendix 3

Quick Reference Guide

Appendix 1

Contact details for support groups

Support	Details	Contact
Antenatal Results and Choices (ARC)	Provides support and information to expectant and bereaved parents throughout and after the antenatal screening.	020 7713 7486 0845 077 2290 info@arc-uk.org www.arc-uk.org
Bliss (for babies born too soon, too small, too sick)	The national charity that supports babies born premature or sick and their families.	0500 618140 enquiries@bliss.org.uk www.bliss.org.uk
Child Bereavement UK	Supports families when a child dies, or when children are bereaved. Provisions include telephone support, online forums, information sheets for families, how to support surviving siblings, professional education.	0800 02 888 40 support@childbereavement.org.uk enquiries@childbereavement.org.uk www.childbereavement.org.uk
Child Death Helpline	A helpline for anyone affected by the death of a child of any age, from pre-birth to adult, under any circumstances, however recently or long ago.	0800 282 986 contact@childdeathhelpline.org www.childdeathhelpline.org.uk
The Compassionate Friends	An organisation of bereaved parents and their families offering understanding, support and encouragement to others after the death of a child or children. They also offer support, advice and information to other relatives, friends and professionals who are helping the family.	0845 123 2304 helpline@tcf.org.uk www.tcf.org.uk
Contact a Family	A national charity providing advice, information and support for any family with a disabled child, whatever the child's condition.	0808 808 3555 www.cafamily.org.uk info@cafamily.org.uk
Cruse Bereavement Care	Promotes the well-being of bereaved people and helps them understand their grief and cope with their loss.	0844 477 9400 helpline@cruse.org.uk www.cruse.org.uk
Multiple Births Foundation	Provides support and advice for families with twins or more.	020 3313 3519 www.multiplebirths.org.uk
Organ Donation	National Tissue Donor Referral Centre (England and Wales)	0800 432 0559

Rainbow Trust Children's Charity	Provides emotional and practical support to families who have a child with a life threatening or terminal illness.	01372 363438 www.rainbowtrust.org.uk
Samaritans	Provide confidential non-judgemental emotional support, 24 hours a day for people who are experiencing feelings of distress or despair.	08457 90 90 90 www.samaritans.org
SANDS (Stillbirth and Neonatal Death Charity)	Offers parents support when their baby dies during pregnancy or after birth. Also have information on post mortem examinations.	020 7436 5881 helpline@uk-sands.org www.uk-sands.org
Sibs	The UK charity for people who grow up with a disabled brother or sister. They support siblings who are growing up or who have grown up with a brother or sister with any disability, long term chronic illness, or life limiting condition.	01535 645453 www.sibs.org.uk
TAMBA (Twins and Multiple Birth Association) Bereavement Support Group	Support and advice for families with twins or more. The helpline is staffed by trained volunteers who are multiple birth parents themselves.	0800 138 0509 asktwinline@tamba.org.uk www.tamba.org.uk
TCF Sibling Support	A project run by The Compassionate Friends which provides nationwide self-help support for people who have suffered the loss of a brother or sister.	0845 123 2304 www.tcfsiblingsupport.org.uk
TfSL (Together for Short Lives)	The UK charity that speaks for all children with life-threatening and life-limiting conditions and all who love and care for them. Provides details of children's hospice services.	0845 108 2201 www.togetherforshortlives.org.uk
Winston's Wish	For children who have been bereaved.	08452 030405 www.winstonswish.org.uk
Benefits Enquiry Line		0800 88 2200 www.makingcontact.org

Appendix 2

Medications and dosages

Reference: British National Formulary for Children (BNFc). BMJ Publishing Group Ltd, RPS Publishing, RCPCH Publications Ltd.

The drug doses below are for neonates unless otherwise indicated in the comments column. Refer to the BNFc for infants older than 1 month of age. Other formularies used in paediatric palliative care include the Association of Paediatric Palliative Medicine Master Formulary. As this guidance is intended for babies on neonatal units the BNFc is referenced.

Drug	Use	Dosage	Route	Comments
Chloral hydrate	Long term sedation	20–30mg/kg up to 50mg/kg 4 times daily	Oral/rectal	
Clonazepam	Seizures Status epilepticus	100mcg/kg over 2 minutes, repeated after 24 hours if required	Intravenous injection	
Diazepam	Seizures	1.25–2.5mg repeated after 5 minutes if necessary	Rectal	
Domperidone	Gastro-oesophageal reflux and stasis	100–300mcg/kg 4–6 times daily before feeds	Oral	
Glycopyrronium bromide	Control of airway secretions and hyper-salivation	40–100mcg/kg 3–4 times daily	Oral	Dose for child 1 month–18 years
Hyoscine hydrobromide	Control of airway secretions and hyper-salivation	250mcg (quarter of a patch to skin) every 72 hours	Transdermal patch applied to hairless area of skin behind ear	
Loperamide	Diarrhoea	100–200mcg/kg twice daily 30 minutes before feed. Increase as necessary up to 2mg/kg in divided doses		Dose for child 1 month–1 year
Midazolam	Status epilepticus	300mcg/kg single dose	Buccal	
		150–200mcg/kg	Intravenous injection	
		1mcg/kg/min, increasing by 1mcg/kg/min every 15 minutes until seizure is controlled. Maximum dose 5mcg/kg/min	Continuous intravenous infusion	

Drug	Use	Dosage	Route	Comments
Morphine	Acute pain/post operative	**Premature infants:** initially by intravenous injection over at least 5 min, 25–50mcg/kg, then by continuous infusion 5mcg/kg/hr adjusted according to response	Intravenous injection and infusion	
		Neonate: initially by intravenous injection over at least 5 min, 50–100mcg/kg, then by continuous intravenous injection 10–20mcg/kg/hr adjusted according to response up to 40mcg/kg/hr.	Intravenous injection and infusion	
		10mcg/kg/hr	Subcutaneous infusion	Dose for infant 1–3 months
	Chronic pain	80mcg/kg every 4 hours adjusted according to response	Oral/rectal	Dose for infant 1–12 months
		150–200mcg/kg every 4 hours adjusted according to response	Subcutaneous injection	1 month–2 years
Omeprazole	Gastro-oesophageal reflux	700mcg/kg once daily orally, increased if necessary after 7–14 days to 1.4mg/kg. Some neonates may require up to 2.8mg/kg once a day	Oral	
Paracetamol	Pain Pyrexia	**Neonate 28–32 weeks postmenstrual age:** 20mg/kg single dose, then 10–15 mg/kg every 8–12 hours as necessary. Maximum 30mg/kg in divided doses	Oral	
		Neonate >32 weeks postmenstrual age: 20 mg/kg single dose, then 10–15 mg/kg every 6–8 hours as necessary. Maximum 60mg/kg daily in divided doses	Oral	
		Neonate 28–32 weeks postmenstrual age: 20mg/kg single dose, then 15mg/kg every 12 hours as necessary. Maximum 30mg/kg in divided doses	Rectal	

Appendix 2

Drug	Use	Dosage	Route	Comments
Paraldehyde	Seizures Status epilepticus	0.4ml/kg as single dose, maximum 0.5ml	Rectal	
Phenobarbitone	Seizures Status epilepticus	20mg/kg	Slow intravenous injection	
		Then: 2.5–5 mg/kg once daily Dose and frequency adjusted according to response	Oral/slow intravenous injection	
Phenytoin	Seizures Status epilepticus	Initially 20mg/kg as loading dose, then 2.5–5 mg/kg twice daily, adjust according to response	Slow injection or infusion	
Ranitidine	Gastro-oesophageal reflux	2mg/kg 3 times daily, maximum 3mg/kg 3 times daily	Oral	
		0.5–1 mg/kg every 6–8 hours	Slow intravenous injection	

Appendix 3

Quick reference guide

1. Management of the infant once a decision to withdraw or withhold life-sustaining treatment has been made: Key principles

1.1 Process of withholding and withdrawing life-sustaining treatment

- Ensure both parents are present and have a face-to-face discussion in a quiet room away from the neonatal unit where possible. Give them the option of inviting other key family members or a close friend to be with them.
- Using phrases such as "Our aim is to help your baby have a pain free peaceful death", "We cannot cure your baby but we will always care for him", "We want to support you through this difficult time" may help.
- Arrange for an interpreter to be present if needed—avoid family members, and especially children interpreting where possible.
- Ensure that parents have privacy, adequate time and opportunity to discuss their views and feelings and to ask questions.
- Enable the junior doctor and the nurse caring for the infant to be present during the discussion, so that they are aware of the process involved, and gain experience.
- If it is necessary to take samples of tissue before death in order to make a diagnosis, this should be clearly explained to the parents. Consider zygosity testing in the case of same sex twins and triplets. Organisations such as the Multiple Births Foundation (See Appendix 1 for details) can help with zygosity testing.
- Agree a time and location for withdrawal of life-sustaining treatment with the parents.
- Explain what will physically happen to the infant, what to expect practically, and if the length of time to death is uncertain.
- If withdrawal of life-sustaining treatment is likely to lead to immediate death explain that the infant may gasp and have colour changes to their face and body.
- Ask if the parents would like to be present at the actual time that life-sustaining treatment is withdrawn. Be mindful that they may prefer not to, and also that they may change their mind. Ask the parents whether they would like siblings or family members to be with them.
- Ask if they would like their infant to be dressed in anything special, or have particular requests such as bathing, or anointing.
- Ask if the parents would like to hold their infant.
- Ask if they would like photos to be taken and invite parents to take handprints and footprints. If parents do not want photos, offer to take some to keep in the medical records, in case they decide they would like them at a later date. Ask parents if they wish to keep any items such as blankets, hats or any other items that were related to the baby's care.
- If the infant is one of a set of twins, triplets or quads, where possible take a photograph of the babies together with the family. This could be incubators or cots close together if that is the only way to do this if the other infant is very sick.
- Ensure the nurse who is allocated to the infant and family does not have another infant to care for. Ask the parents if they would like the nurse to be present behind the screen or in the room with them—if they prefer privacy explain how they can call the nurse and advise that he/she will return intermittently.
- Let parents know that it is possible for their baby to remain with them after death if they should wish. If a post mortem examination is to be carried out it is not advisable to keep the body outside of a cool room or mortuary for longer than 4-6 hours. Parents should be informed that it is possible to see their baby after the body has been taken to the mortuary and following the post mortem. It may be possible for the body to be transferred to a cool room in a children's hospice.
- It may be possible for the family to take the infant home after death until the funeral. Please refer to local guidelines and policies.
- Consider providing written information.

Appendix 3

1.2 Pain relief

- All infants receiving palliative care must have consideration given to relief of pain and discomfort. This includes the type of medication, the dose, route of administration and the likely duration of need—consideration should be given to the use of formal tools to assess pain.
- Should the infant have intravenous access in place, this route is preferable in the immediate period after discontinuation of life-sustaining care.
- If an infant is already receiving analgesic medication this should be continued—if opiates are to be initiated, an initial bolus dose should be given before commencing an infusion so that adequate analgesia is achieved promptly. The dose may be increased or reduced depending on ongoing assessment of distress and development of tolerance—if relevant, parents should be made aware that opiates while relieving pain and distress also suppress respiratory drive and may hasten death.
- If the intravenous route is not available and adequate analgesia cannot be achieved through oral medication, a subcutaneous infusion may be necessary. Intramuscular medication is never appropriate. For rapid symptom management, buccal medication can be considered, usually in addition to longer acting medication via the enteral route or subcutaneous infusion.
- Non-narcotic analgesia such as paracetamol and oral sucrose may be used for less severe pain or in combination with narcotic analgesics.
- Refer to Appendix 2 for a list of suggested medication and doses.
- Non pharmacological interventions to reduce pain and discomfort should be used in conjunction with analgesic medications—these include a calm environment with minimal noise and light stimuli, non-nutritive sucking with a pacifier, music and positioning with arms and legs flexed close to the trunk using a blanket or rolls and massage.
- Assist the parents to hold their baby.
- Support continued suckling at the breast if the mother wishes.

1.3 Other symptom control

- Symptoms such as seizures and difficulty with secretions should be assessed and treated appropriately.
- Refer to Appendix 2 for medications and doses.

1.4 Physiological monitoring

- Invasive techniques such as invasive blood pressure monitoring should be discontinued. Cardiac and saturation monitors should also be disconnected prior to disconnecting mechanical ventilation.
- The infant should be monitored for physical signs that suggest discomfort (crying, whimpering, panting, tachycardia, excessive secretions, dry mucous membranes).
- Blood tests and blood gas measurements should no longer be carried out.
- Once life-sustaining support has been withdrawn intermittent physical examination with auscultation of the heart rate should be continued by the nurse or doctor caring for the infant.

1.5 Fluids and nutrition

- The goal of treatment is comfort, not the provision of nutrition.
- In those infants able to tolerate milk feeds their ongoing provision should be determined by their clinical condition and the cues that the infant demonstrates.
- Oral nutrition should only be withheld if it is felt that providing it will cause pain or discomfort.
- If vomiting is a problem, the volume of enteral feeds should be reduced appropriately.
- It may be appropriate to allow the infant to suckle at the breast if able to do so.
- In those infants in whom the duration between the withdrawal of life-sustaining care and death is expected to be short, it is reasonable to cease all feeds if it is felt feeding could cause distress, and to discontinue intravenous hydration and nutrition.

- If death does not follow the withdrawal of life-sustaining care, or if palliative care is instituted in an infant where the provision of hydration and nutrition is the sole intervention maintaining life, then considering stopping this is appropriate only if to do so will not result in hunger or distress to the infant. Any such decision should involve discussion with the parents.
- Any decision to continue to provide intravenous nutrition and hydration should be taken in the light of the pain and discomfort to the infant of continuing to provide fluid and nutrition (eg need for central or peripheral venous access).
- If the infant is discharged home or to a hospice for palliative care, arrangements to continue or discontinue medically provided fluids and nutrition will need to be made in advance and the parents supported accordingly.
- Gastrostomy, nasogastric and jejunostomy feeding will also require parent training and professional community support.
- The benefits of surgery to allow feeding either via the intravenous route or via the enteral route must be balanced against the burden of the intervention and the prolongation of death.
- Refer to the algorithm under section 1.5.

1.6 Ventilation and oxygen

- Explain to the parents what is going to happen and when it will happen and which member of staff will be present.
- Explain that death may not be immediate and that the infant may survive for a prolonged period.
- Explain how the infant will be cared for.
- Decide in advance which member of staff will be responsible for the actual removal of the endotracheal tube/turning the ventilator off.
- Aspirate the nasogastric tube and also consider not feeding the infant just prior to extubation.
- Turn off the alarms of the ventilator and monitors prior to disconnecting these.
- Suction the endotracheal tube before removal.
- Give the parents the choice of being present and holding their infant.
- Withdrawal of less invasive forms or respiratory support such as nasal continuous positive airway pressure and nasal cannulae oxygen may be appropriate if a baby is dying and continued provision of respiratory support only serves to prolong death.

1.7 Location of care

- The principles of palliative care should be consistently applied regardless of location.
- The best available space with privacy and comfort for parents and family should be used.
- Discuss with parents if they prefer to stay in the neonatal unit with a screen for privacy or move to a side room if available.
- If the mother is receiving care herself (for example after a caesarean section) consider providing palliative care on the postnatal wards in a private area that does not compromise her own care and provide nursing support for the infant.
- Consider transfer to a hospice, especially if the duration between the withdrawal of life-sustaining treatment and death is expected to be days rather than hours—ensure this option is available before discussing it with the parents.
- When an infant is transferred to a hospice supported by a palliative care team, it is recommended that there is a designated senior neonatal doctor with whom the palliative care team can liaise after discharge. This is particularly important should there be a change in the infant's condition after discharge.
- Consider the possibility of transfer home or to a hospital closer to home, prior to extubation. The family may have established relationships with staff at the local hospital or may wish to have family nearby. This can only be done if there is sufficient support available at the chosen location to support extubation and provide ongoing care.
- Liaise with community palliative care services and the transport team to ensure services and support can be provided before discussing options with families.
- Tailor care to the individual needs of the infant and the family, but be realistic.

Appendix 3

- If a decision to institute palliative care has been made in the antenatal period consider offering parents the opportunity to visit a hospice.
- Throughout this process it is important to communicate regularly current information with other specialties that may be hospital or community based. This could include GPs, health visitors, community nursing teams and maternity services involved in the care of the infant and who can support the family.

2. Conflicts and decision making: Key principles

2.1 Conflicts between parents and staff

- Allow parents time to consider the decision and arrange for the senior clinician to see them again after the initial meeting in which the decision to institute palliative care was reached.
- Reassure them that withdrawal of life-sustaining treatment does not mean that care of their infant will be withdrawn but rather that there will be a shift in the focus of care. Staff should not appear judgmental should a parent indicate wish to continue life-sustaining support.
- If relevant, explain that life support technology is not in itself a curative treatment and does not change the baby's underlying condition.
- Explore the reasons behind the parents' views of the situation.
- Suggest parents might find it helpful to discuss their feelings with family, friends or spiritual/religious figures—offer access to hospital religious representatives if appropriate.
- Offer parents a second opinion either with another senior clinician within the team or outside the hospital of care.
- Consider approaching a clinical ethics committee if access to one exists or medical mediation services if appropriate.
- While awaiting the outcome of these actions, provide parental reassurance that the care of their infant will continue unchanged.
- Staff should not appear judgmental about a parent's decision to continue life-sustaining support.

2.2 Conflicts among members of staff

- All members of staff whatever their level of seniority should be included in discussions about the ongoing care of the infant and in decisions about appropriateness of continuing life-sustaining support—the weight of the opinion of each member of the clinical team will depend on their experience but the ultimate decision rests with the senior clinician in charge.
- Regular, scheduled and well attended unit meetings, psychosocial meetings and multidisciplinary case discussions promote team cohesiveness, and healthy team functioning, and are key means of reducing conflict between staff, and reducing the potential for escalation.
- An external facilitator may be helpful where there is significant conflict.
- Neonatal units should have access to a clinical psychologist and staff should be aware of other sources of support (Appendix 1).
- Reflective practice sessions facilitated by a trained member of staff can be helpful both before and after a decision to institute palliative care has been made—staff should be offered debriefing after the death.
- Chaplaincy/multi-faith chaplaincy/spiritual care team members can provide support for staff especially when strong beliefs are a factor.

3. Support for parents and families: Key principles

3.1 Religious, pastoral and spiritual support

- Staff should assess the spiritual and religious needs of the family and if appropriate, refer to the chaplaincy/multi-faith chaplaincy/spiritual care team or ask if the family would like to have their own religious or spiritual representative contacted.
- The family's religion should be clearly documented as part of the admission history taking process.
- Staff should be aware that each family is individual and will have different beliefs, and cultural and religious backgrounds.
- Be respectful of the family's religious beliefs and rituals. If you are unsure of rituals or correct procedures, ask the family.

- Be mindful that the mother and the father may have different religious or cultural beliefs.

- While reasonable to consider offering families who describe themselves as 'not religious' or 'non-practicing' the offer of a prayer or a blessing, their views should be respected.

3.2 Psychological and emotional support

- The primary providers of immediate emotional and psychological support to families on the neonatal unit are frontline nursing and medical staff—they should be empowered through awareness of the support available, to offer appropriate choices to families tailored to their needs.

- Parents should be informed of the availability of support, but it must be parents' decisions as to whether they take up the offer. There is some evidence that the most benefit is realised by those who actively request support.

- Staff should be aware that families might show their distress in different ways—they may be tearful, withdrawn, short-tempered or angry.

- Some families may be adept at communicating the full extent of their distress whereas other may find their capacity to communicate diminished in times of stress.

- Families' needs for support vary. Some may wish frequent appointments immediately following the death of an infant—others may wish for shorter, more specific support, such as how best to support a sibling.

- Parents with a surviving twin/triplet require specific bereavement support as they may be caring for another sick baby on the unit or even a healthy child at home.

- Support may be provided by a range of professionals, such as a clinical psychologist, child psychotherapist, or counselling psychologist—what is important is that the professional providing support is knowledgeable and experienced in working with parents who have had an infant on a neonatal unit and of specific issues regarding multiple births, especially where there is a surviving co-sibling.

- Information on any financial support available to assist with the funeral and time taken out of work should be provided.

- Inform families of the name of the staff member who will contact them and when, and provide written information about this and how to access on going bereavement support, Provide further support where necessary if parents experience secondary losses, such as a change in their relationship.

- Support should be offered by the neonatal team for as long as required and when appropriate refer to other support services.

- For other organisations that provide support for parents refer to Appendix 1.

- Inform mothers of the options available for lactation suppression should this be required.

4. Post mortem examinations and organ donation: Key principles

- If parents raise the issue of post mortem examination themselves, discussion before the infant's death is acceptable.

- A post mortem examination should be offered to all parents of infants that die even if the cause of death is obvious. This allows the detection of unsuspected problems. The person taking consent should be trained to do this and the parents provided with written information.

- If the cause of death is unclear, discuss the need for a post mortem examination with the relevant authority (Coroner/Procurator).

- Some parents may wish to donate their infant's organs—it is important to establish if this is possible and if not, then to explain why this is the case. Donation of heart valves is usually considered for infants whose death is expected within a specific time period. This is possible only if the infant is above 37 weeks gestation with a weight of 2.5 kg and above and the valves must be harvested within 48 hours of death. Currently the only Heart Valve Bank retrieving heart valves from neonates is the Oxford Heart valve Bank. The United Kingdom Hospital Policy for Organ and Tissue Donation (UK Transplant, April 2003) refers to organ donation from anencephalic infants in the event that a suitably matched recipient is waiting. If heart donation, which is the only suitable organ for donation from anencephalic infants is not possible the option of heart valve donation may be discussed with the parents. This type of donation is rare in the UK and further guidance is awaited.

Appendix 3

5. Staff support: Key principles

- Neonatal staff should have access to a clinical psychologist and providers of spiritual care.
- Staff should receive training in the principles of palliative care and sensitive communication with parents.
- All members of staff whatever their level of seniority should be included in any discussions about the ongoing care of the infant and in decisions about the appropriateness of continuing intensive support.
- Staff should be offered debriefing after a death. The debriefing could take the form of focused reflective practice sessions facilitated by a trained member of staff or external facilitator. This is distinct from a more traditional medical debrief in that it allows a space for team members to develop a shared narrative of events, appreciate practice that has gone well, and consider alternative ways that families might be supported.
- All staff should be allowed and supported to care for families who have a baby receiving palliative care, rather than allowing the expertise to be concentrated in a small group of workers. In this way all staff can appreciate the experience of the families as well as the needs and experience of those that care for them.
- There are papers that suggest that caring for babies at the end-of-life should be voluntary for staff and if staff members feel unable to care for such infants they should be assigned to other duties. The General Medical Council (Section 'Personal Beliefs and Medical Practice' under Guidance on Good Practice) states that it is not acceptable to opt out of treating a particular patient or groups of patients because of personal beliefs or views about them. The Nursing and Midwifery Council's Code of Conduct in the UK states that nurses should not discriminate in any way against those for whom they provide care. The consensus within the GDG is that members of staff who express their reluctance to care for infants at the end-of-life should receive support and training to enable them to fulfil this role.

Chelsea and Westminster Hospital NHS
NHS Foundation Trust

369 Fulham Road
London
SW10 9NH

Main Switchboard
+44 (0) 20 3315 8000

Website
www.chelwest.nhs.uk

@ChelwestFT

Chelsea and Westminster Health Charity