



**Palliative Care (Supportive and End of Life Care)  
A Framework for Clinical Practice  
in Perinatal Medicine**

**Report of the Working Group August 2010**

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# The British Association of Perinatal Medicine

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**Palliative care (supportive and end-of-life care)**  
**A Framework for Clinical Practice in Perinatal Medicine**  
**Supplement report of the working group**

**Summary: key components of the framework.**

Decisions about perinatal end of life care planning should be based on the best possible information on the diagnosis and prognosis of the underlying condition.

Palliative care should only be considered if the fetus or baby has a candidate condition.

If a woman decides to continue her pregnancy knowing that her baby has a condition that will cause significant disability but is non lethal, the baby is not necessarily eligible for palliative care.

Joint decision making with parents, open communication and clear documentation are essential for good decision making and the delivery of the care plan.

An individualised integrated care plan should be drawn up after multidisciplinary discussions between clinical specialists, the parents and the team that will provide palliative care. Antenatal and postnatal care of the mother need to be included in the care plan.

The care plan should cover all foreseeable outcomes. It should be flexible enough to allow for changes in the condition of the mother or the baby and in the parents' views and wishes.

**Introduction**

Advances in antenatal diagnosis of fetal abnormalities, obstetric care, neonatal care and care at the margins of viability have all increased need for decision making about end-of-life care for the fetus and neonate. These decisions present clinicians and parents with new and difficult challenges.

**1. Background**

Antenatal diagnoses of lethal abnormalities and of conditions which are associated with a significant risk of death are being confirmed earlier in pregnancy. A plan for palliative care may be needed at any stage in pregnancy, especially when the diagnosis is made at or beyond 20-22 weeks gestation. Palliative care may also be needed in the early perinatal period, for example because of extreme prematurity, or the diagnosis of a condition with a very poor long-term prognosis.

Recent guidance from the Nuffield Council of Bioethics (Nuffield 2006) and the British Association of Perinatal Medicine working group on the clinical care of extremely preterm infants supports the decisions of clinical staff and parents not to resuscitate or institute intensive care when this would not be in the baby's best interests. The Department of Health is developing guidance on end-of-life care for adults but not yet for the fetus, neonate, or infant.

**The aim of this document** is to provide guidance for clinical staff on clinical decision making and on developing integrated care pathways for perinatal palliative care. It highlights key practice points to help clinical staff to develop consistent high quality care and help develop uniform standards of care wherever families are cared for. It should be used in conjunction with other guidance in particular the ACT Neonatal Pathway 2009.

## **2. Definition**

Perinatal palliative care is defined here as the planning and provision of supportive care during life and end-of-life care for a fetus, newborn infant or infant and their family in the management of an appropriate candidate condition.

## **3. Candidate conditions for perinatal palliative care**

These can be considered in five broad Categories.

*Category 1.* An antenatal or postnatal diagnosis of a condition which is not compatible with long term survival, e.g. 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, e.g. 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, e.g. severe hypoxic ischemic encephalopathy.

*Category 5.* Postnatal conditions which result in the baby experiencing “unbearable suffering” in the course of their illness or treatment, e.g. severe necrotizing enterocolitis, where palliative care is in the baby’s best interests.

## **4. Criteria for establishing a candidate condition**

### *Criteria for Categories 1 and 2*

Palliative care should only be considered when the diagnosis of an abnormality has been confirmed. Karyotypic abnormalities and single gene defects may be diagnosed by CVS, amniocentesis or cordocentesis in the antenatal period. Structural abnormalities are usually picked up at routine ultrasound screening. Antenatal diagnosis of a structural abnormality should be confirmed by a fetal medicine consultant. In many cases, other investigations such as MRI or 3D or 4D ultrasound should be used to confirm the diagnosis or provide further information. Cardiac anomalies should be assessed by a perinatal cardiologist using fetal specialist echocardiography.

These investigations should be followed by a multidisciplinary team (MDT) discussion to agree the diagnosis and prognosis and to consider any implications for maternal health. This is not essential in fetal conditions for which there are simple definitive diagnostic tests and an agreed prognosis, e.g. anencephaly, however it *is* essential in the case of many *structural* abnormalities. Communication aids such as video conferencing and

video telemetry in real time should be considered when the specialist unit and the referring unit are in different localities. The diagnosis and prognosis is then explained and discussed with the family.

If either the parents or members of staff are still uncertain about the diagnosis or prognosis, a second opinion, either internal or external, should be sought. This should be arranged by the department, although some parents may want to choose another tertiary centre and this should be facilitated.

### **Deciding on either palliative care or termination of pregnancy**

In Categories 1 and 2, both the option of continuing the pregnancy with palliative care and the option of terminating the pregnancy should be discussed with the parents. These discussions are usually held with the fetal medicine team.

Palliative care is not an option if an abnormality which does not fulfill Criteria 1 or 2 is diagnosed during pregnancy. Knowing that the baby will live but with significant impairment, the mother can choose to terminate or to continue her pregnancy.

When an abnormality is diagnosed antenatally but it is not clear that it fulfils the criteria for Category 2, the mother should be told that decisions about the baby's care can only be taken after the birth. As active rather than palliative care could be appropriate, a mother who is certain that she cannot cope with a disabled child may wish to have a termination.

It is important to note that not all pregnancies which fulfil the criteria for late termination of pregnancy under section E of the Abortion Act, would be suitable for palliative care. For example, most fetal medicine specialists would regard severe ventriculomegaly (with a posterior horn diameter of >15mm) as grounds for termination of pregnancy at 24 weeks or beyond. However, this condition would not automatically be grounds for instituting perinatal palliative care unless the infant's condition also fulfilled the criteria for Categories 4 or 5 above.

#### *Criteria for Category 3*

The British Association of Perinatal Medicine guidance document '*The Management of Babies Born Extremely Preterm at Less Than 26 Weeks of Gestation*' outlines situations at the margins of viability when withholding or withdrawing active resuscitation is an appropriate option.

#### *Criteria for Category 4*

It is important that the diagnosis and prognosis of a condition in Category 4 are as accurate as possible. In order to achieve this, it may be helpful to have an appropriate second opinion or investigations such as MRI, other imaging, and genetic testing. If these are not available locally, transfer to an appropriate centre should be considered.

The prognosis for the baby should be agreed by at least two paediatricians/neonatologists. These may be internal or external second opinions, depending on the unit's referral pathways. An MDT meeting should be considered if there is uncertainty about the prognosis, or if further opinions from other disciplines (e.g. paediatric neurology) are required.

### *Criteria for Category 5*

In order to establish whether a baby is experiencing “unbearable suffering”, two senior paediatricians/neonatologists, either internal or external, should assess the infant to decide if the degree of suffering can reasonably be described as “unbearable” and that palliative care would be in the best interests of the baby.

## **6. Planning perinatal palliative care with families**

When planning perinatal palliative care, it is essential that there should be multidisciplinary discussions involving the parents, a named hospital midwife from the hospital, a community midwife, a senior obstetrician, a senior paediatrician/neonatologist and a neonatal nurse. In Categories 3, 4 and 5 there may be less involvement of obstetric and hospital midwifery staff. In all cases, in addition to this core group, it may be appropriate to involve further paediatric subspecialties, the GP, health visitor, and paediatric palliative care team.

If the core group is not local, the outcome of these discussions must be communicated as soon as possible to the local team that is caring for the family. Parental consent for this should be obtained beforehand. After the first core group meeting, a written summary of the discussion should be sent to all participants including the parents, to the local team, and to any other professionals involved in the case. It is important that the summary is written in plain English and that all medical terms are explained clearly so that parents will understand it. Ensuring that the parents are kept informed and understand the care plan may help to guard against misunderstandings and misinformation from other sources (e.g. internet).

Consideration should be given to the location of meetings between parents and professionals and, in particular, the area in which parents will have to wait beforehand. Parents should have a choice whether to wait in antenatal clinics or paediatric clinics with families who are experiencing uncomplicated pregnancies or have children with them, or have more privacy.

Because a large number of professionals are involved, it is very important that the care plan has a named coordinator. It is important that parents are invited to contact a member of core group if they need to and that they know how to get in touch. This will help to reduce unnecessary distress and minimise problems with communication.

## **7. Planning perinatal palliative care with the local team**

Although the diagnosis and assessment of suitability for palliative care will be made by the core team, care will often be delivered by a different local team. It is essential, therefore, that there is optimal communication between these two teams. It is also important that the local team has the relevant clinical experience and confidence to care for the baby at birth and to deliver the supportive and end-of-life care plan.

## **8. Components of the palliative care plan**

### *8.1 Planning obstetric care – antenatal*

The mother should continue to receive routine antenatal care. However, if the fetal diagnosis increases the risk to maternal health, appropriate antenatal care should be arranged (e.g. to manage the likelihood of polyhydramnios in a woman whose baby has anencephaly). Fetal medicine assessments should continue alongside antenatal care.

Whether or not the mother's health is at risk, her emotional needs and those of her partner must be taken into account at this very difficult time. For example, they should not be asked to sit in a waiting room with women with healthy pregnancies or to attend standard antenatal classes. The staff whom they meet should also be informed of the situation beforehand so that they do not unintentionally say things that cause additional distress.

### *8.2 Planning obstetric care – intra-partum*

Mothers should be encouraged to discuss their wishes for labour and birth before preparing a birth plan. An explicit care plan should also be developed in conjunction with the mother, which should include the question of fetal monitoring (normally not recommended), the action to be taken in the event of fetal distress, the conduct of the delivery, and how the baby will be handled and cared for at and after the birth. In general, the aim should be to wait for spontaneous labour and to avoid unnecessary intervention.

In certain situations, intervention may be needed: For example, a tendency for labour to be very prolonged when a fetus has anencephaly; a Caesarean section if labour would increase the risks for the mother. A mother of a baby with a lethal abnormality may ask for a Caesarean to increase the chances of the baby living for a brief time after the birth. In such cases, detailed discussion with the obstetric consultant involved is essential.

### *8.3 Place of delivery*

In some cases, delivery may be planned in a tertiary centre where staff are experienced in providing appropriate post-natal management of the infant. Alternatively the mother may return to her local hospital for the birth.

Parents who opt for home births should be supported if possible. In this case the palliative care plan for the baby will need to be agreed with the community team. However, in some cases home birth will not be desirable for maternal health reasons, or because of a lack of experienced community midwives. The local supervisor of midwives may need to be involved in decisions in these circumstances.

### *8.4 Confirming the diagnosis after the birth*

In some situations, a rapid assessment of the infant by a senior paediatrician/neonatologist may be needed to confirm a candidate condition for palliative care. In other situations, such as anencephaly, there will be no uncertainty and no rapid assessment is needed. Occasionally, specific tests may be helpful, e.g. rapid karyotype of cord blood in the case of anomalies suggestive of a lethal aneuploidy.

### *8.5 Planning care for multiple pregnancies*

If one or more babies have a lethal or serious abnormality and one or more babies have not, individual care plans should be drawn up for each baby. It is important that staff are aware that parents in this situation may be torn between spending time with the dying baby or babies, and being with the baby or babies that stand a good chance of survival. It is also important that staff realise that having a live baby does not "make up" for a baby who dies.

### *8.6 Postnatal care for the mother*

It is important that women receive, as a minimum, normal postnatal care and emotional support from community midwives. Parents are likely to be grieving, and other family members may not be able to offer sufficient support and comfort. Ongoing support from

the family GP and health visitors is therefore essential.

## **9. Support for the family**

Families will require support at many levels. Parents will be shocked, frightened and stressed by the knowledge that their baby has a life threatening or lethal abnormality or having a baby in a neonatal unit. They may also be grieving for the loss of a normal pregnancy and birth and the planned for and dreamed of future. Parents of twins and other multiples may have to cope with additional complex and conflicting emotions, for example, dealing simultaneously with end-of-life decisions for one baby, whilst remaining hopeful for another.

Parents in these situations are likely to be both physically and emotionally exhausted. The mother may not have recovered from the birth and may be missing out on some of her postnatal care. Travelling to and from the unit, expressing milk and spending hours in the neonatal unit are extremely tiring and stressful. Partners may be juggling visits to the baby, support for the mother and work. Parents may also have other children to care for. If they live a long way from the unit they face the additional stress of long and costly journeys. The extended family may also be fearful and grieving and may be unable to offer emotional or practical support.

Many parents also have financial worries. A study by Bliss (2007) of 169 parents showed that many suffered significant financial hardship as a direct result of having a baby in a neonatal unit. Many families commented that they accumulated considerable debt during the time their baby spent in hospital, and that they still hadn't 'caught up' sometimes years down the line.

### *9.1 Good Communication*

Fear, stress and anxiety make it difficult for parents to understand and take in complex and distressing information. It also makes it hard for them to think clearly and to take what are likely to be the hardest decisions of their lives. Privacy and time to think are important. False reassurance and platitudes are always unhelpful. The use of clear, unambiguous language is vital, especially when the parents' first language is not English.

### *9.2 Psychological support*

Parents really appreciate staff who show genuine care and concern for their baby and who show understanding and empathy for them. Taking time to listen to parents concerns is important. Many parents will also be grateful if staff suggest that they start to create and collect mementoes. These will give parents some tangible evidence of their baby's existence and their time together and can be very important in the months and years to come. Some mementoes can be collected before the baby dies, others afterwards. These might include photographs, foot and hand prints, a lock of hair, clothes the baby has worn, cot tags, identity bracelets, certificates and copies of consent forms. Antenatal ultrasound pictures can be very helpful after the death, and some parents may even want to help bathe and dress their baby for the first and last time. Some parents may want to involve other family members and for example, take photographs of the baby with brothers and sisters or with grandparents.

Staff should also consider whether the family should be offered the opportunity to see a



trained counsellor / bereavement counsellor. Some parents may benefit from the support of an advocate, and staff should be supportive and accepting if this is the case. General practitioners, the primary care team and paediatric palliative care team may also be helpful in providing general support, symptom relief and referral for specialist counseling. Parents should be offered written information about the relevant voluntary organisations and support groups such as ARC, Bliss, Sands and Contact a Family. Ideally, staff should also have a small supply of the relevant leaflets that these charities produce for parents.

### *9.3 Spiritual or personal beliefs*

Care should reflect parents' personal and/or spiritual wishes. It is essential that staff do not make any assumptions about these but ask parents sensitively what they would like and, where appropriate, help to organise this. Most hospitals now have access to chaplains from a range of different faiths. Where appropriate, parents should be asked if they would like the relevant chaplain to visit. Some may want to bring in their own religious leader and a few may want him or her to have an opportunity to talk to the doctor in charge of the baby's care.

### *9.4 Financial and social support*

Parking and restaurant discounts are available at some hospitals and parents should be told about these as soon as their baby is admitted to the unit. Ideally the unit should keep leaflets about the various maternity and paternity rights and benefits to give to parents. Staff should ensure that mothers know that they must apply for benefits within three months of the baby's birth.

Staff should discuss with the family whether they need support from social services at each stage, e.g. a family with a baby who is at home having supportive and end-of-life care may need help with travel arrangements to school for their other children.

### *9.5 Planning care of baby while alive with parents*

This refers to the period of time before a baby dies. This period of time can range from hours/days to weeks typically. Care of the baby needs to be discussed and planned. Important areas to plan are the approach to resuscitation, nutrition, pain relief and comfort care. The appropriate place for this period of care should be discussed with the parents and the MDT team, which health care professionals are best to deliver and or support this care and what support parents will need.

There is guidance on resuscitation of newborn infants. Comfort and dignity of the baby receiving resuscitation should be maintained. The potential suffering and loss of dignity for a baby that prolonged periods of resuscitation or ventilation can lead to when families experience a delay in arrival should be considered.

## **10. Planning end-of-life care**

Parents should be given the opportunity to discuss preferences and priorities relating to religious or personal observance before and around the time of the death.

### *10.1 Predicting the Timing of death*

A baby with a serious or lethal abnormality diagnosed during pregnancy may die at any time during pregnancy and through to infancy. For some babies it can be very difficult to predict a time of death. Whatever the condition, the possible or likely timing of the baby's death and any uncertainties should be discussed with both parents and staff by the

MDT. Parents and staff should be informed as soon as possible of any changes.

### *10.2 Place of death*

Depending on the situation and the level of supportive and end-of-life care required, the baby may die on the delivery suite, in a postnatal ward, the neonatal unit, at home or in a children's hospice. The lead paediatrician or neonatologist should discuss with the parents where the baby will be cared for, explain what is likely to happen, and take their wishes into account as far as possible. If a baby is being discharged home, or to a children's hospice for supportive and end-of-life care, the health of the mother must also be considered and suitable practical and emotional support arranged as needed. Transport should be organised to allow time at home or the hospice prior to the period of end of life care.

### *10.3 Organ donation*

If relevant, the parents should be told about the option of organ donation (e.g. heart valves), this would depend on the absence of congenital anomaly in the donate tissue.

### *10.4 Changes in appearance of the dying baby.*

Staff should explain to parents the physical changes that are likely to occur as their baby dies and should discuss with them whether they want to see and hold their baby whilst dying/or after death. It is important to make it clear to the parents that they can change their minds at any time.

### *10.5 Counselling about post mortem examination*

A senior member of staff should sensitively encourage the parents to consent to a postmortem investigation and examination so that maximum information can be obtained. In some cases it may be appropriate to discuss this sensitively in the antenatal period. A post mortem examination may both confirm the diagnosis and provide information which may help the parents to come to terms with their loss. The information gained may also be important if and when the parents think about another pregnancy.

### *10.6 Follow-up support for parents*

Leaving the neonatal unit with empty arms and for the last time after the baby has died is extremely hard. Many parents have built up a rapport with the staff and sometimes with the parents of other babies. However difficult the previous days and weeks have been, visiting the unit has provided the parents with some contact with people who understand what they are going through and has given some purpose and pattern to their day. All they leave the unit with is their memories. Some parents appreciate an open invitation to visit the unit again if they want to.

Staff should ensure that the mother's GP and the local primary care team are informed by phone about the baby's death so that they can offer ongoing care and support. Staff should also check that parents have the contact details of the relevant charities that offer care and support to bereaved parents such as Sands, Bliss, and the Child Bereavement Trust.

Staff should also give parents verbal and written information about how to register the baby's death and birth if this has not already been done and about arranging a funeral. Parents should be offered a follow-up appointment when the results of all outstanding investigations including the post mortem are available. Coordinating this follow up with other specialists involved can be helpful in minimising visits for the family. As well as discussing the results, parents should be given the opportunity to discuss the

events surrounding their baby's care and death. If possible, the core team and/or the team delivering palliative care should be present at this appointment. Where appropriate, parents should also be offered an appointment with a genetic counsellor.

#### *10.7 Certification of death*

If a baby is born with signs of life before 24 weeks, is stillborn at or after 24 weeks, or is born alive and subsequently dies, the parents must register the stillbirth or birth and death. They should be given both verbal and written information about how and where to do this. A plan should be in place to identify the doctor who will sign the 'Cause of Death Certificate' for live born infants. This has to be a doctor who has seen the baby alive and is certain about the cause of death. It would be advisable to talk to the coroner if the doctor has not seen the child prior to death or within 14 days of death.

When an expected death occurs at home, there is no urgency for the family to call a doctor. The care plan should indicate who and when to inform when a baby dies at home. If a family calls an ambulance when the baby dies, the police are automatically informed. This can unnecessarily add to the family's distress. The care plan is particularly important at this point and parents should keep a copy of the care plan at their home.

#### *10.8 Taking a deceased baby home following death in hospital*

There is no legal reason why parents should not take the remains or body of their baby out of the hospital at any gestation. However, for the protection of the parents and to avoid misunderstandings, staff should give parents some documentation to take with their baby's body. A sample form designed for this purpose can be downloaded from the Sands website: <http://www.uk-sands.org/Improving-Care/Resources-for-health-professionals/Forms-and-certificates-to-download.html>

### **11. Conflict resolution**

Conflict can occur at many levels, for example, between parents; between the parents and the MDT or individual members of staff; between the referring and tertiary centres; and between hospital and community services. Whether and how a conflict is resolved will depend on its specific nature and on the parties involved. Key general principles of resolution include optimal communication and recourse to second or third opinions. Mutual respect between members of the MTD and respect for the parents' views and feelings are also essential. If necessary, ethics committees or mediation bodies can be consulted.

### **12. Education and training for clinical staff**

This area of clinical practice is developing as candidate cases emerge. Optimum training and education programmes need to be developed and available for all relevant clinical staff.

### **13. Staff support**

Consideration should be given to providing departmental psychological support for all clinical staff who are involved in the delivery of perinatal palliative care. Models of this form of support exist, for example, in paediatric palliative care teams. These provide external support both for individual clinicians and for the clinical team as a whole.

## Appendix 1

### Examples of candidate conditions

This method of considering diagnostic and prognostic certainty can be helpful in agreeing candidate conditions. There must be prognostic certainty of the underlying condition to make decisions on eligibility for palliative care. Diagnostic certainty is not always possible. Category 5 requires consideration of “best interests of the baby”.

#### Anencephaly

	<b>Prognostic certainty</b>	Prognostic uncertainty
<b>Diagnostic certainty</b>	<b>yes</b>	<b>no</b>
Diagnostic uncertainty	<b>no</b>	<b>no</b>

*Anencephaly is a condition which has diagnostic certainty and prognostic certainty. It is a condition which does fulfil the criteria for palliative care.*

#### Bilateral renal disease

	<b>Prognostic certainty</b>	Prognostic uncertainty
<b>Diagnostic certainty</b>	<b>rarely</b>	<b>no</b>
Diagnostic uncertainty	<b>yes</b>	<b>no</b>

*Severe antenatal bilateral renal disease with anyhydramnios is a condition where there can be diagnostic uncertainty. If there is prognostic certainty then it can fulfil the criteria for palliative care.*

#### Ventriculomegaly-severe

	<b>Prognostic certainty</b>	Prognostic uncertainty
<b>Diagnostic certainty</b>	<b>rarely</b>	<b>yes</b>
Diagnostic uncertainty	<b>no</b>	<b>no</b>

*Severe ventriculomegaly is a condition with diagnostic certainty. The prognosis can be uncertain and therefore may not fulfil the criteria for palliative care.*

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