



# Palliative care (supportive and end of life care)

## A framework for clinical practice in Perinatal medicine

“Palliative care for [fetus, neonate or infant] with life limiting conditions is an active and total approach to care, from the point of diagnosis or recognition, throughout the child’s life, death and beyond. It embraces physical, emotional, social and spiritual elements and focuses on the enhancement of quality of life for the [neonatal infant] and support for the family. It includes the management of distressing symptoms [provision of short breaks] and care through death and bereavement.” *ACT 2009*

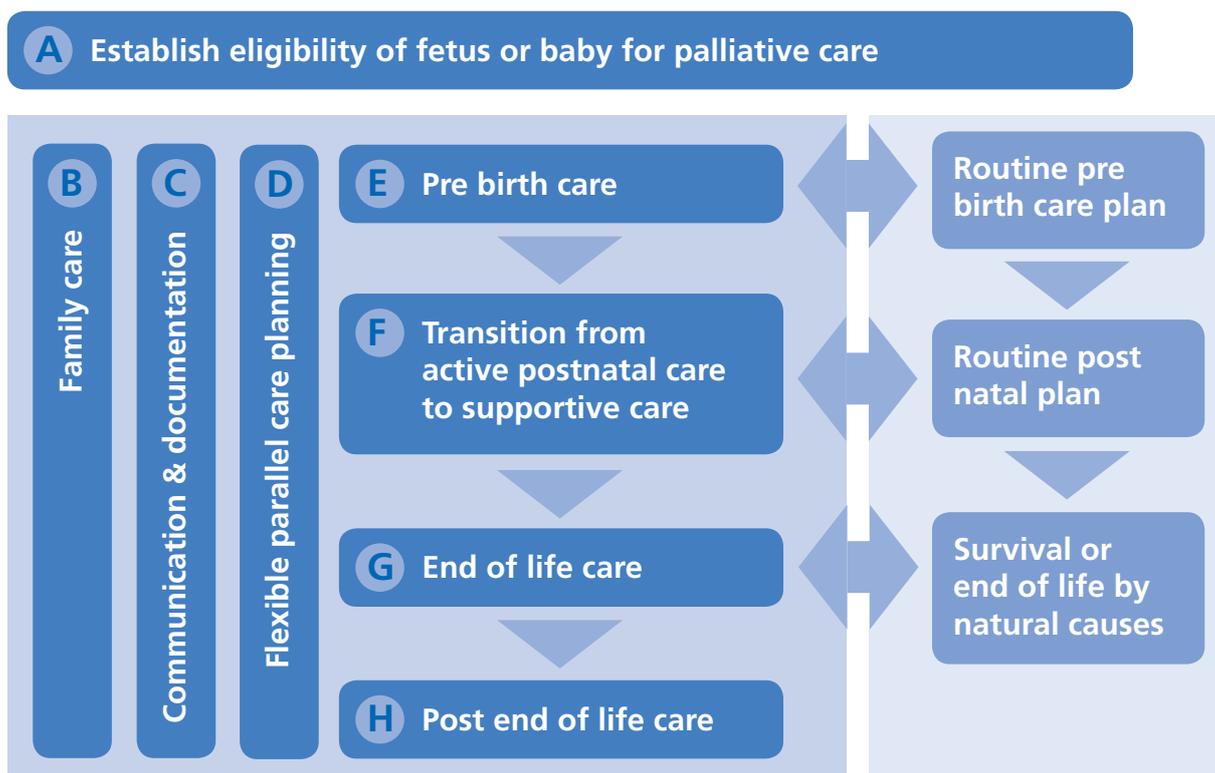
Perinatal palliative care is further described here as the holistic management of supportive and end of life care following multidisciplinary agreement on eligibility for a fetus, newborn or infant and their family. It can also include the period of transition from active routine care in to palliative care.

The key components of holistic palliative care planning have been divided into eight stages (A-H). Agreement on eligibility for palliative care and achieving patient comfort are paramount (A). The stages of family care and communication and documentation should occur throughout the care planning and delivery (B, C). Stages E, F, G and H represent points of care transition. These stages will be helpful to consider when developing care plans.

Palliative care planning involves multidisciplinary team planning with professionals from maternity, obstetric, neonatal, community and children’s hospice services and families. Choices in care may vary up until the end of life and there may be a transition in to and out of active, supportive and end of life care. Flexible and parallel care planning during these periods should be continuously considered (D).

Family and staff support during the period of planning for and providing palliative care should be offered. ARC, Bliss and SANDS are organisations that have contributed to this document and provide useful information for families.

### Stages of palliative care planning



## **A Establishing Eligibility for palliative care before or after birth**

### **Diagnosis and prognosis**

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

### **Eligibility**

Palliative care can be considered for fetuses and babies with conditions that are not compatible with long term survival, or that carry a significant risk of death or impairing quality of life, or that cause unbearable suffering (RCPCH / BAPM / ACT).

### **Antenatal planning**

Antenatal diagnosis should involve fetal medicine specialists. MDT discussions with paediatricians and other specialists may be required to agree on diagnosis and prognosis of a condition. It is important to remember that if a woman decides to continue her pregnancy knowing that her baby has a condition that will cause significant disability impairing quality of life but is not life limiting, the baby is not necessarily eligible for palliative care.

## **B Family Care throughout palliative care planning and delivery**

### **Psychological support**

Staff should consider whether the family including siblings should be offered the opportunity to see a trained counsellor / bereavement counsellor. 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 counselling.

### **Creating memories**

Many parents will also be grateful if staff explain and facilitate the option to create and collect mementoes. These might include antenatal scan pictures, photographs, foot and hand prints, a lock of hair, clothes the baby has worn, cot tags, identity bracelets certificates and copies of consent forms.

### **Support of spiritual/personal belief**

Care should reflect parents' personal and/or spiritual wishes. Staff should ask parents sensitively what they would like and, where appropriate, help to organise this.

### **Social support**

Parking and restaurant discounts are available at some hospitals. Parents should be guided to information about benefits and maternity and paternity rights. Staff should ensure that mothers know that they must apply for benefits within three months of the baby's birth. Specific needs for social support should be discussed at each stage.

## **C Communication & documentation throughout palliative care planning period**

### **Decision making and planning**

It is essential that there should be multidisciplinary discussions and decision making involving the parents and a core team which may include a named hospital or community midwife, a senior obstetrician, a senior neonatal, general, community or palliative care paediatrician, a neonatal nurse and allied specialist doctors (e.g. surgeons/geneticists).

### **Timing of discussions**

Discussions and decision making may be taken during the antenatal period, at birth or at any time after birth.

### **Primary care team**

It is vital to involve or inform members of the primary care team about palliative care planning as soon as possible: GP, children's community nursing team, health visitor, paediatric palliative care team and children's hospice, if appropriate, as they may be part of the team delivering palliative care.

### **Key member of staff**

At all times the parents should have the name and contact details of a key member of staff (recorded on the care plan) and staff covering them when on leave.

## **C Communication & documentation throughout palliative care planning period**

### **Care plans**

The responsibility of care may be passed from regional to local units, and to the community. Written care plans should be in plain English or appropriate translation and all medical terms should be explained clearly so that parents will understand them. Parents should receive all information documented in hand held notes. The care plan may need to be altered to allow for changes in the place of care, the condition of the mother or the baby and the parents' views and wishes.

## **D Flexible parallel care planning**

Whilst there are many conditions where there is reasonable certainty of death during fetal and neonatal life, there are babies who survive longer than expected during supportive and end-of-life care. It is vital that all care planning is continuously reviewed in the best interests of the baby. There should be parallel planning for transition periods into and out of active, supportive and end-of-life care.

## **E Pre birth care**

### **Routine antenatal care**

Routine antenatal care should still be provided once a palliative care plan is being developed with a family. The emotional needs of the family must be taken in to account at this difficult time. For example whether a woman wishes to sit in a waiting room with other women with healthy pregnancies or would prefer more privacy. 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. In the case of multiple pregnancies individual care plans should be drawn up for each baby.

### **Alert system**

Consider alert systems (e.g. SANDS teardrop sticker) with parental consent to help identify families to clinical and administrative staff.

### **Intrapartum Care plan**

An explicit care plan should 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.

### **Delivery & Cesarean Section**

In general, the aim should be to wait for spontaneous labour and to avoid unnecessary intervention. Cesarean section may be indicated if labour would increase the risks to the mother or a mother may request a Cesarean Section to increase the chances of the baby living for a brief time.

### **Place of delivery**

Explore the options for place of delivery including regional or local unit, or home delivery. Consider privacy and emotional needs of family when identifying the delivery room.

### **Staff at delivery**

Discuss, specify and forewarn staff who should or should not be present at the delivery (paediatricians, chaplaincy, family members).

### **Resuscitation at delivery**

Non resuscitation or limitations to resuscitation should be discussed and regularly reviewed.

### **Postnatal care of baby and mother**

Please follow section F, G, and H to complete care planning. The suitability of the care plan should be confirmed after birth by a senior paediatrician or neonatologist. Occasionally, specific tests may be helpful, e.g. rapid karyotype of cord blood in the case of possible lethal aneuploidy such as trisomy 13. It is important that women receive, as a minimum, normal postnatal care and emotional support from midwives.

## **F** Postnatal care plan following antenatal or postnatal eligibility

### Transition of care from active to palliative care

In some cases there is likely to be a gradual transition from active care in to palliative care. Active treatment and monitoring may be continued during this period while parents and staff re evaluate what serves the best interest of the baby. There may need to be consideration of the length of time of the transition phase so the baby's interests are maintained.

### Supportive care

#### **Physical comfort care**

Continue to practise basic care to minimise distress; positioning, skin care, mouth care, human contact including breast feeding and skin to skin contact. If the baby is comfortable the temperature does not need to be monitored. Developmental needs of the baby should not be forgotten.

#### **Pain, distress and agitation**

Assess and treat any underlying causes of pain. Consider paracetamol, ibuprofen. If not sufficient use morphine by the route best tolerated by the baby: oral, buccal, intravenous or subcutaneously. (refer to CBNF and symptom control manual ACT). Increase doses by 30-50% as needed to ensure the baby is comfortable. There is no upper limit to the dose of morphine for relief of pain or distress even in the knowledge that this may cause respiratory depression (double effect). Buccal or subcutaneous midazolam can be used if morphine is not fully effective. However it is illegal to give any medication with the main intention of hastening death.

#### **Nutrition, Feeding, GI symptoms**

The goal of feeding is to provide comfort and reduce distress from hunger, with growth as a secondary outcome. The route of feeding should be what is most suitable for the baby. Parenteral fluids and nutrition, nasogastric tube feeding are rarely indicated. Breast feeding may be comforting for the baby and mother. It may not be possible to maintain hydration.

#### *Vomiting*

Consider reducing feeds to the level the baby will tolerate and anti reflux treatment if reflux symptomatic.

#### *Constipation*

Opiates may constipate. If causing distress consider using lactulose or glycerine suppositories.

#### *Urinary retention*

May be caused by opiates. Consider abdominal pressure and rarely catheterisation.

#### *Respiratory secretions*

Should only be treated if distressing to the baby. Consider use of hyoscine patches.

#### **Investigations, monitoring and Treatment**

Monitoring is not necessary, but may be used if helpful for parents. Investigations should only be performed if the results might lead to treatment that will improve the baby's quality of life or help with the diagnosis and management of subsequent pregnancies. Treatments such as antibiotics, oxygen, anticonvulsants, anti reflux medication, insertion of rickham reservoir or VP shunts, hernia repair can have a role in symptom control. Immunisations should be given as per national immunisation programme.

#### **Resuscitation plans**

Limitations to resuscitation should be discussed and reviewed regularly. Comfort and dignity of the baby should be maintained. Consider the potential suffering and loss of dignity for a baby that prolonged resuscitation or ventilation can lead to.

## **G** End of life care planning

### Place of care

Depending on the level of supportive and end-of-life care required, the baby may die in utero, on the delivery suite, postnatal ward, neonatal unit, at home or in a hospice. If a baby is being discharged home for supportive and end-of-life care, the health of the mother must also be considered and appropriate care organised.

### Staff leading end of life care

The staff who will be responsible for managing this period should be identified in advance.

## **G End of life care planning**

### **Transition to end of life**

It is important to explain to the family the details of care e.g. how and when an ET tube and intravenous canulae are removed, and monitoring leads disconnected.

### **Physical changes in appearance**

Physical changes that are likely to occur as a baby dies should be discussed and whether families want to see and hold their baby whilst he or she dies and/or after death. Terminal gasping should be explained in order to reassure parents that this is not an indication of suffering and usually not treated. Parents should be made aware that the time until death can vary from minutes to hours and possibly days.

### **Post mortem**

A senior member of staff should sensitively discuss consent to post-mortem investigations and examination to help clarify diagnosis and management of subsequent pregnancies.

### **Organ donation**

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

## **H Post death care**

### **Confirmation of death and Death certificate**

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, 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. The care plan is particularly important at this point. Paperwork for the **Child death overview panel** will need to be completed. There is usually input to the panel regarding neonatal deaths.

### **Registration of death**

If a baby is born with signs of life before 24 weeks, or is born alive and subsequently dies, the parents must register both the birth and death. If a baby is stillborn at or after 24 weeks, the parents must register the stillbirth. They should be given both verbal and written information about how and where to do this.

### **Taking deceased baby home**

Parents can take the remains or body of their baby out of the hospital at any gestation. Staff should give parents some documentation to take with their baby's body. Sample forms 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>

### **Funeral (burial or cremation)**

The options for a funeral and how this can be organised should be sensitively discussed with the family.

### **Communication and Follow up**

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. Some parents appreciate an open invitation to visit the unit again if they want to. Parents should be offered a follow-up appointment when the results of all outstanding investigations are available. 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. Consideration should be given to avoiding all ongoing routine mail from NHS and non NHS services. These sites are useful. [www.mpsonline.org.uk](http://www.mpsonline.org.uk) email [babymyps@dma.org.uk](mailto:babymyps@dma.org.uk).

### **Staff support**

Staff should be provided with informal and formal support during the period of providing palliative care and afterwards.

## Authors

Edile Murdoch (Chair)<sup>1</sup>; Andy Cole<sup>2</sup>; Finella Craig<sup>3</sup>; Clare Daly<sup>3</sup>; Sharon English<sup>4</sup>; Sally George<sup>5</sup>; Bryan Gill<sup>6</sup>; Lindis Harris<sup>7</sup>; Anthony Kaiser<sup>8</sup>; Christoph Lees<sup>1</sup>; Alex Mancini<sup>9</sup>; Mike Miller<sup>10</sup>; Judith Schott<sup>11</sup>; Norman Smith<sup>12</sup>; Helen Statham<sup>13</sup>.

**1** Cambridge University Hospitals NHS Foundation Trust   **2** Bliss   **3** Great Ormond Street   **4** Leeds General Infirmary   **5** ARC   **6** BAPM  
**7** Maidstone & Tunbridge Wells NHS Trust   **8** Guys and St Thomas' NHS Foundation Trust   **9** Chelsea and Westminster Hospital  
**10** Martin House Hospice   **11** SANDS   **12** Aberdeen Royal Infirmary   **13** Centre for Family Research, Cambridge

## Useful addresses

**ACT – Association for Children's Palliative Care** [www.act.org.uk](http://www.act.org.uk)

### ARC (Antenatal results and choices)

Offers information and support for parents throughout antenatal testing and when a significant abnormality is detected. [www.arc.org](http://www.arc.org)

**Basic Symptom Control Guideline** [www.act.org.uk/core/core\\_picker/download.asp?id=160](http://www.act.org.uk/core/core_picker/download.asp?id=160)

### Bliss

The premature baby charity, offers support, advice and information for families of babies in intensive or special care, including bereaved families [www.bliss.org.uk](http://www.bliss.org.uk)

**Children's BNF** <http://bnfc.org/bnfc/>

### Child Bereavement Charity

Support, information and resources for bereaved families and for professionals [www.childbereavement.org.uk](http://www.childbereavement.org.uk)

### SANDS (Stillbirth and neonatal death charity)

Offers information resources and support to anyone affected by the loss of a baby. [www.uk-sands.org.uk](http://www.uk-sands.org.uk)

## Drug dosages

Drug dosages can be found at the following sites:

**Basic Symptom Control Guideline** [www.act.org.uk/core/core\\_picker/download.asp?id=160](http://www.act.org.uk/core/core_picker/download.asp?id=160)

**Children's BNF** <http://bnfc.org/bnfc/>

The table below shows the drug dosages for morphine

### Drugs used to treat pain in neonates (plan to adopt ACT drug dosages)

Drug	Dose	Comments
Morphine IV	40 to 100 micrograms/kg	For acute pain – can be repeated as needed
	10-20 microgram/kg/hour continuous infusion	Usual starting dose for infusions in non ventilated babies – can be titrated according to response
Morphine Subcutaneous	150 microgram/kg for acute pain	Diamorphine is preferable for using subcutaneously
Morphine Sulphate Orally	Double the total daily IV morphine requirements can be titrated and given 4 hourly	Morphine requirements are very variable
Diamorphine IV	100 microgram/kg	For acute pain
	2.5-7 microgram/kg/hour	Continuous infusion in non ventilated babies – can be adjusted to response
Diamorphine Subcutaneous	Total daily oral morphine dose: subcutaneous diamorphine dose = 1:0.33	

## Key documents

- ACT A Neonatal Pathway for Babies with Palliative Care Needs 2009 [www.act.org.uk](http://www.act.org.uk)
- ACT (Association for Children's Palliative Care) 2009. Making Life-limited Children and Young People Count: A Framework and Guide For Local Implementation.
- A Framework for Clinical Practice at the time of Birth. Arch Dis Child FNN Online October 6, 2008 as 10.1136/adc.2008.143321
- Association for Children with Life-Limiting and Terminal Conditions and their Families, now known as Association for Children's Palliative Care (ACT), 2009. Assessment of Children with Life-Limiting Conditions and their Families – A Guide to Effective Care Planning. ACT.
- Association for Children with Life-Limiting and Terminal Conditions and their Families, now known as Association for Children's Palliative Care (ACT) & the Royal College of Paediatrics and Child Health, 1997. The Guide to the Development of Children's Palliative Care Services – Report of Joint Working Party. ACT/RCPCH.
- Better Care: Better Lives. Department of Health 19 February 2008.
- Bliss (2007) Financial help for families Downloadable from Bliss Publications, [www.bliss.org.uk](http://www.bliss.org.uk)
- Critical care decisions in fetal and neonatal medicine: ethical issues. Nuffield Council on Bioethics 2006 [www.nuffieldbioethics.org](http://www.nuffieldbioethics.org)
- End-of-life Care Strategy – promoting high quality care for all adults at the end of life. DOH 16/07/2008.
- Ferrell B.R., 1998. The Family. In: Doyle et al. Textbook of Palliative Medicine. 2nd Ed. Oxford, Oxford University Press.
- Guide to the development of children's' palliative care services. Joint working party RCPCH 1997
- Pregnancy Loss and the Death of a Baby: Sands Guidelines for Professionals. J Schott, A Henley, N Kohner, Sands, 2007
- Rainbows Children's Hospice, 2006. Basic Symptom Control in Paediatric Palliative Care. 6th Ed. Rainbows Children's Hospice.
- The Management of Babies born Extremely Preterm at less than 26 weeks of gestation British Association of Perinatal Medicine.
- Withholding or Withdrawing Life Sustaining Treatment in Children – A Framework for Practice. Royal College of Paediatrics and Child Health, 2nd Ed. May 2004.