

Recognising uncertainty: an integrated framework for palliative care in perinatal medicine

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ABSTRACT

In perinatal medicine, the number of babies with life-limiting or life-threatening conditions is increasing and the benefits of providing palliative care with a holistic, interdisciplinary approach are well documented. It can be particularly challenging, however, to integrate palliative care into routine care where there exists uncertainty about a baby's diagnosis or potential outcome. This framework, developed collaboratively by the British Association of Perinatal Medicine (BAPM) and the Association of Paediatric Palliative Medicine (APPM), offers supportive guidance for all healthcare professionals working in perinatal medicine across antenatal and neonatal services. It explicitly acknowledges that palliative care is not just for babies who are dying or who will certainly die in early life; incorporating a palliative approach into antenatal and neonatal care for all babies with an uncertain outcome can be particularly valuable. The framework provides guidance on recognising babies who may benefit from palliative care and outlines the key elements of perinatal palliative care: holistic family support, empowering parents to be parents, parallel planning, symptom management and loss and bereavement care. It provides recommendations for the delivery of palliative care services, advocating for a unified approach that involves all members of the perinatal team, supported by specialist services as needed. This framework calls for a shift in the philosophy and practice of perinatal care to integrate palliative care into the everyday and to recognise and embrace the challenge of uncertain prognosis.

INTRODUCTION

Most newborn babies cared for by perinatal teams survive. Advances in fetal and neonatal care mean that mortality rates in neonatal intensive care units (NICU) have decreased over the past two decades in high-income countries like the UK.^{1,2}

However, the prevalence of children with life-limiting or life-threatening conditions has risen over recent years, with the largest increase seen in infants under the age of 1 year.³ New forms of diagnostic testing (such as genome sequencing and advanced imaging technologies before or after birth) are identifying a growing cohort of fetuses and babies with potentially life-limiting illness.⁴ Furthermore, success in acute stabilisation of critically ill newborns born extremely prematurely⁴ or with major congenital malformations can be followed by a long period when outcome is uncertain. Some such babies will die after a long period of intensive

care while others will live with medical complexity and additional care needs linked to the underlying disease and its treatments. Owing to these factors, the number of babies who are now eligible for palliative care is increasing. It has been estimated that at least 2500 babies each year in England and Wales cared for in NICUs would benefit from palliative care.⁵

Perinatal teams have for some time recognised and embraced the importance of palliative care for newborn infants with terminal illness.⁶ Children's palliative care is life-long supportive care. It is all-encompassing, wide-ranging care, provided to children and their families in the knowledge that strong, consistent relationships are key to providing the best care.⁷ Traditionally, however, uncertainty about whether the baby will or could survive has been a barrier to considering a palliative approach to care.⁸ Professionals and families sometimes worry that they would be 'giving up hope' by agreeing to (or even discussing) a palliative care plan. But waiting until there is certainty about outcome can mean that some of the significant potential benefits of palliative care are lost. It can impede planning, it can compromise the care of those babies who do end up dying in infancy or early childhood, and it can result in families feeling unprepared for the loss of their child.

It is this central challenge for perinatal care that we focus on in this framework.

To inform the scope of this framework, in collaboration with Together for Short Lives, we undertook a survey of perinatal healthcare professionals. Our findings from 152 doctors, nurses, midwives, allied healthcare professionals, clinical support workers and service managers highlighted the need for information on identifying babies with palliative care needs, decision-making practices, how and when to involve and refer to paediatric palliative care teams and how and when to use parallel and advance care plans. The framework also applies key learnings from direct feedback from families and from recent research studies involving both families and healthcare professionals. Evidence shows that healthcare inequalities, including socioeconomic and racial disparities, have recognised consequences on maternal and perinatal mortality,^{9–11} further emphasising the need to ensure equitable access to palliative care services.¹²

The Framework for Practice has been developed by consensus as a joint initiative by the British Association of Perinatal Medicine (BAPM) and Association of Paediatric Palliative Medicine, taking into

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account the input of a large working group and follows wide consultation. BAPM is grateful for input from parent representative organisations including Bliss, SANDS, Child Bereavement UK and Together for Short Lives.

The central message of this framework is that palliative care is not just for those babies who are dying or who will certainly die early in life. Where there is uncertainty about survival or diagnosis and outcome, integrating a palliative approach into antenatal and neonatal care can be *particularly valuable and important*. For example, this includes many 'high-risk' extremely preterm infants,¹³ even while they are continuing to receive intensive care. Research has shown that families welcome palliative care being delivered alongside treatments aimed at long-term survival¹⁴ and that palliative care is compatible with simultaneously honouring hope.¹⁵

This framework is for all healthcare providers in perinatal services who are caring for babies and their families facing an uncertain prognosis and outcome. Key elements aim to support a broader use of a palliative care approach, parallel care planning and the integration of specialist palliative care services.

AN INTEGRATED MODEL OF PALLIATIVE CARE

There are different terms that might be used.

'Palliative care' refers to an active approach to the care of patients with life-limiting conditions from the time of diagnosis through to death and bereavement. It embraces physical, emotional, social and spiritual needs and focuses on the enhancement of quality of life and support for the patient's family.¹⁶ Palliative care is not the same as end-of-life care, though it includes such care as and when that is appropriate.

'End of life care' refers to the care of a patient in the dying phase, including symptom management, decision-making about appropriate treatments and family support.

'Supportive care' is sometimes used to refer to an approach to care, which aims to support patients and families to live as well as possible by providing high-quality pain and symptom control alongside practical and psychological support.^{17 18} Supportive care is provided for patients in the setting of uncertain outcome, for example, patients who may recover but also are at risk of dying. Many families and healthcare providers are comfortable referring to this as 'palliative care', while others find the term 'supportive care' more accessible or preferable.

In this framework, we propose an integration of palliative care into perinatal medicine at several levels.

First, we encourage teams to use 'Palliative Care' as an umbrella term, which encompasses the full spectrum of supportive care and end of life care. This broader definition of palliative care

includes a common approach to the holistic care of babies and their families with potentially life-limiting conditions (figure 1). This includes many babies who are not receiving end of life care, those for whom the outcome is not certain and some who may recover fully and live a normal lifespan.

Second, we propose an integration of palliative care into perinatal care at a practical and operational level. Palliative care will often be provided alongside and in addition to elements of routine survival-focused care. (This is sometimes misleadingly called 'Active Treatment', but the latter is an imperfect term since palliative care involves an active approach and many active interventions.)

Third, palliative care should be 'integrated' in that it involves general elements provided by the same neonatal and perinatal care teams who provide other elements of care, together with (in some cases, and as required) the support of specialist palliative care teams (see the Delivering perinatal palliative care section).

RECOGNISING BABIES WHO MAY BENEFIT FROM PALLIATIVE CARE

Here are three different ways of recognising babies who may benefit from palliative care (figure 2):

The diagnostic approach

Babies may be diagnosed before or after birth with a condition that is certainly or potentially life-limiting.

Provision of palliative care following the diagnosis of certainly life-limiting conditions such as anencephaly or trisomy 13 is uncontroversial.

Babies may also be diagnosed with a *potentially* life-limiting condition (box 1). Such babies can benefit from palliative care even if there is a plan to provide or continue treatments directed at survival such as surgery or intensive care.¹⁹ Some babies will exceed expectations and many babies who have palliative care needs will survive to discharge.⁵

Multidisciplinary team and family perspective

Babies may be at risk of dying even if they do not have a specific diagnosis of a life-limiting condition.⁵ Members of the multidisciplinary team (eg, bedside nurses, allied health professionals, psychology and medical staff) and parents should be encouraged to share their concerns. Such concerns may be a useful prompt for further discussion and formal consideration of a baby's potential palliative care needs.

"I knew the doctors were worried about something and not sure what to say. I just wanted to know what it was and be

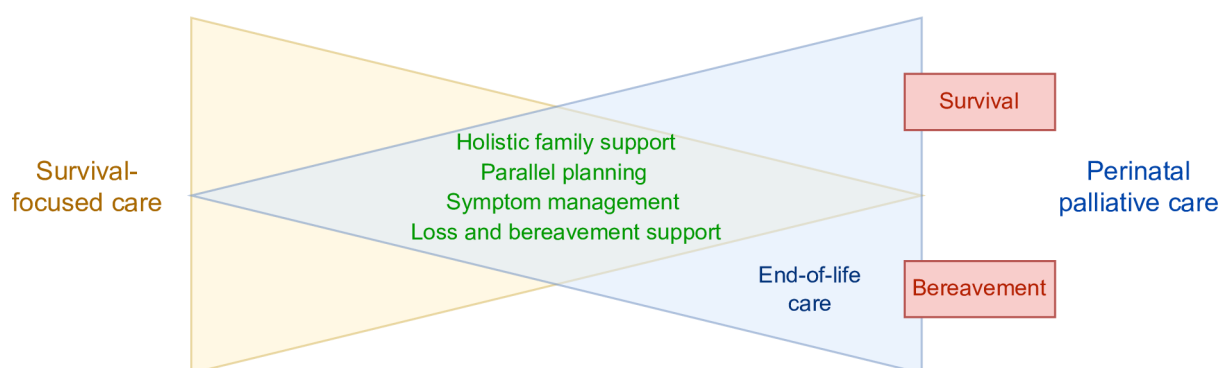


Figure 1 Palliative care in the perinatal setting. Palliative care can offer support (including elements of symptom management, family support, planning and anticipatory bereavement support) alongside survival-focused treatment. (Adapted from the Bow Tie model by Philippa Hawley⁵³).

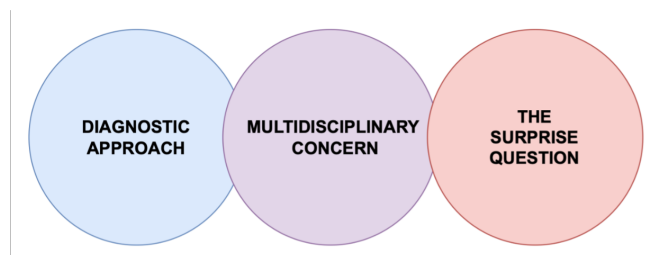


Figure 2 Three ways of identifying babies with palliative care needs.

involved, I didn't need them to have all the answers. Not knowing for weeks and weeks was so worrying." [Parent experience]

Consideration of palliative care does not require uniform agreement by the treating team and parents. Disagreement often indicates an uncertain prognosis and potential life-limiting condition.^{20 21}

Screening: the surprise question

Another approach (adapted from one used more widely in older patients) would be for clinical teams to proactively ask a modified 'surprise question'.^{22–24} 'Would it be a surprise if this baby died (in the short or longer term)?'. Teams may find it helpful as a regular part of multidisciplinary meetings to ask the surprise question of all babies in the intensive care unit. Where the answer is 'no' (ie, it would not be a surprise)—that should prompt the team to actively consider a palliative approach to care.

(We note below that there is a need for formal evaluation of this and other screening tools for identifying babies with palliative care needs before and after birth.)

Communicating with families

Once a baby has been recognised as having the potential to benefit from palliative care, it is important that this is communicated with family members and with other healthcare professionals in a way that effectively communicates prognostic information but that also responds to the emotions generated by the conversation.²⁵ This will often involve acknowledging that there is uncertainty and will require iterative conversations with families about their understanding of the illness and the prognosis, their hopes and fears and what matters most to them as the trajectory of the illness becomes clear.²⁶ See online supplemental appendix B for suggestions about discussing palliative care with families.

Box 1 Examples of potentially life-limiting conditions. See online supplemental appendix C for a longer list of conditions

- ⇒ 'High-risk' extremely premature infants, for example, not only those born at 22 or 23 weeks gestation but also others born later with risk factors such as severe growth restriction.
- ⇒ Infants with univentricular congenital heart disease.
- ⇒ Newborn infants with brain injury and high risk of severe disability, for example, Sarnat III hypoxic-ischaemic encephalopathy, severe intraventricular haemorrhage.
- ⇒ Postnatal exome sequencing indicates diagnosis with the potential to lead to death in early childhood.



Figure 3 Elements of palliative care.

KEY ELEMENTS OF PERINATAL PALLIATIVE CARE

For many babies, palliative care will (at least initially) be an *addition* to other elements of care and would not necessarily involve a change of approach or withdrawal of life-sustaining treatment.

There are five key elements in the provision of perinatal palliative care as represented by [figure 3](#). The needs of babies and families will differ and will likely change over time, needing regular review. Elements of palliative care will in many cases be introduced gradually.

Support: holistic family support

Having a baby with a certainly or potentially life-limiting condition will inevitably have a huge impact on parents, siblings and the extended family.^{27 28} Care planning should include conversations about a family's wider needs and how these can be planned for. Family support includes addressing financial and social needs, the needs of the whole family (siblings, grandparents, foster parents, stepparents, etc) and spiritual and cultural wishes. In the case of a multiple birth, the care and prognosis of neonatal siblings may need additional consideration. The help of additional professionals may be needed, for example, psychology, social work, family support workers, chaplaincy. Specialist sibling support sessions and activities, as well as support for parents and the wider family, are often available through children's hospices.^{25 29}

"I wished the doctors and nurses had talked to me earlier about what this was going to mean for me and the family. I had two kids at home, one at school. My family are not nearby and can't cope with it all and my partner's boss can't give him more leave." [Parent experience]

Many families will value having early access to practical support such as clear guidance around siblings and wider family visiting, local childcare, parking and accommodation.

Empower: supporting parents to be parents

Parents who have been through the experience of a neonatal death have described the importance of having their role and

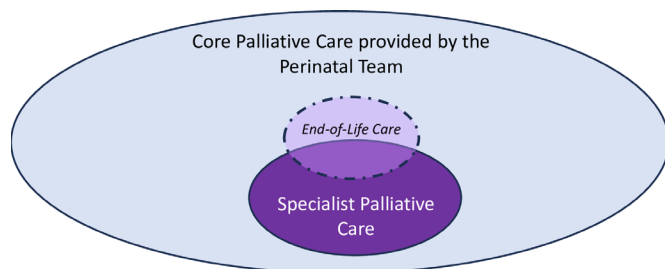


Figure 4 Interface of services delivering perinatal palliative care.

identity as a parent recognised.³⁰ Empowering parents to be a central part of Family Integrated Care for their baby,³¹ to participate in parenting tasks (such as feeding, bathing and dressing) and facilitating physical contact with their baby where possible is of paramount importance. In multiple birth scenarios, parents may want to consider bringing all babies from the pregnancy together (depending on their individual condition) for these activities. With appropriate support, parents can also provide other more specialised elements of care (eg, stoma care, medications, positioning aids). Particularly where survival-focused interventions are no longer thought to be appropriate, there should be increased flexibility around meeting other key goals such as cuddles and feeding. Perinatal teams may be concerned about offering feeds in certain conditions (eg, gut atresias) but where a baby is receiving end of life care, it can be appropriate to offer small drops of feed and to involve parents in this process. Neonatal nursing staff can play a crucial role in delivering these aspects of palliative care.

While navigating uncertainty about a baby's future, it can be easy to neglect to celebrate the joys in the everyday. Both before and after a baby is born, parents can be empowered to celebrate and record significant milestones and take enjoyment from shared experiences together as a family and with their wider community (eg, through antenatal classes and parent support groups).

Plan: parallel planning

For those babies with potentially life-limiting conditions, there can be considerable uncertainty around prognosis.

When diagnosed antenatally, it may be impossible to predict the baby's postnatal course, for example, how long they will survive for, or what support they might require. This uncertainty may be additionally complicated if there is more than one fetus to consider in a multiple pregnancy. For babies being cared for on the neonatal unit, they may experience multiple life-threatening episodes and undergo high-risk procedures, where curative treatment may be feasible but may fail. Managing this uncertainty can be immensely difficult for both parents and professionals.^{32,33} Planning for the future at times of great uncertainty has been shown to be comforting for both parents and children.³⁴⁻³⁶

Parallel planning refers to the process of planning for life while also planning for the possibility of deterioration or death.³⁷ It allows families and professionals to prepare for a range of possible outcomes in settings of uncertainty.³⁸ It requires acknowledging uncertainty and making plans for different contingencies. It includes discussing with parents their wishes in the event of serious deterioration including potential end of life care. Where appropriate and helpful, those wishes can be documented in advance care plans before or after birth. These are formal documents setting out priorities and agreed plans for responding to

acute changes. These plans should be reviewed regularly and in response to changes in a baby's condition. They should be used to document discussions that have been held with parents or carers and do not need to be signed by family members. They do not prevent a parent from being able to change their mind about their wishes at the time of an acute deterioration (see further discussion in the Summary section, and links in online supplemental appendix D). Specialist palliative care teams can provide support for parallel and advance care planning.

Treat: symptom management

Babies with a life-limiting or potentially life-limiting illness may experience a wide range of symptoms including pain, breathlessness, agitation, seizures and feed intolerance. Neonatal teams have expertise in managing these symptoms but should consider involving specialist palliative care teams for babies with complex or refractory symptoms.³⁹⁻⁴² In some cases (particularly if a baby is being discharged home), it will be helpful to develop and document a symptom management plan with specific guidance on pharmacological and non-pharmacological approaches to managing symptoms. These plans should be developed with the support of a neonatal or paediatric palliative care pharmacist.

Loss: grief and bereavement care

All families of babies with palliative care needs will experience loss. Even if the baby recovers, parents potentially experience loss of a normal pregnancy or birth experience, anticipatory loss (at the possibility or expectation that their baby may die) and trauma relating to experiences during birth or in NICU.⁴³

After the death of a baby, parents and the extended family will require bereavement support.⁴⁴ Ongoing contact with the staff who cared for their child can be a great source of support to families.⁴⁵ Specialist psychology support may be accessed via maternal mental health services, neonatal units, specialist paediatric palliative care teams and/or children's hospices.⁴⁶

Care of the baby after death is an important element of bereavement care and parents may wish to participate in the physical care of their baby's body after death as well as memory-making activities. Some families may also wish to explore the option of taking their baby home or to a hospice after death with the support of cooling facilities.⁴⁷ Consideration should be given to providing lactation care, drawing on the support of the local infant feeding team. This includes the option of milk donation as well as anticipatory guidance around lactation suppression, for all mothers facing the possibility of a stillbirth or neonatal death.^{48,49}

Although neonatal organ donation is currently rare, in babies where there may be potential for neonatal tissue and/or organ donation this should trigger early discussion with the local Specialist Nurses in Organ Donation.⁵⁰

It is important to give families an opportunity to feed into the institutional, regional and national processes for review after a baby dies such as the Child Death Review Meeting and the Perinatal Mortality Review Tool. Even in cases when a baby does not die, but has experienced palliative care needs, collecting feedback from families is essential to service improvement.

In situations where a family experiences the loss of a twin, triplet or higher order multiple, there may be the additional complexity of needing to care and support surviving siblings. Please see online supplemental appendix D for information resources on supporting bereavement from a multiple birth perspective.

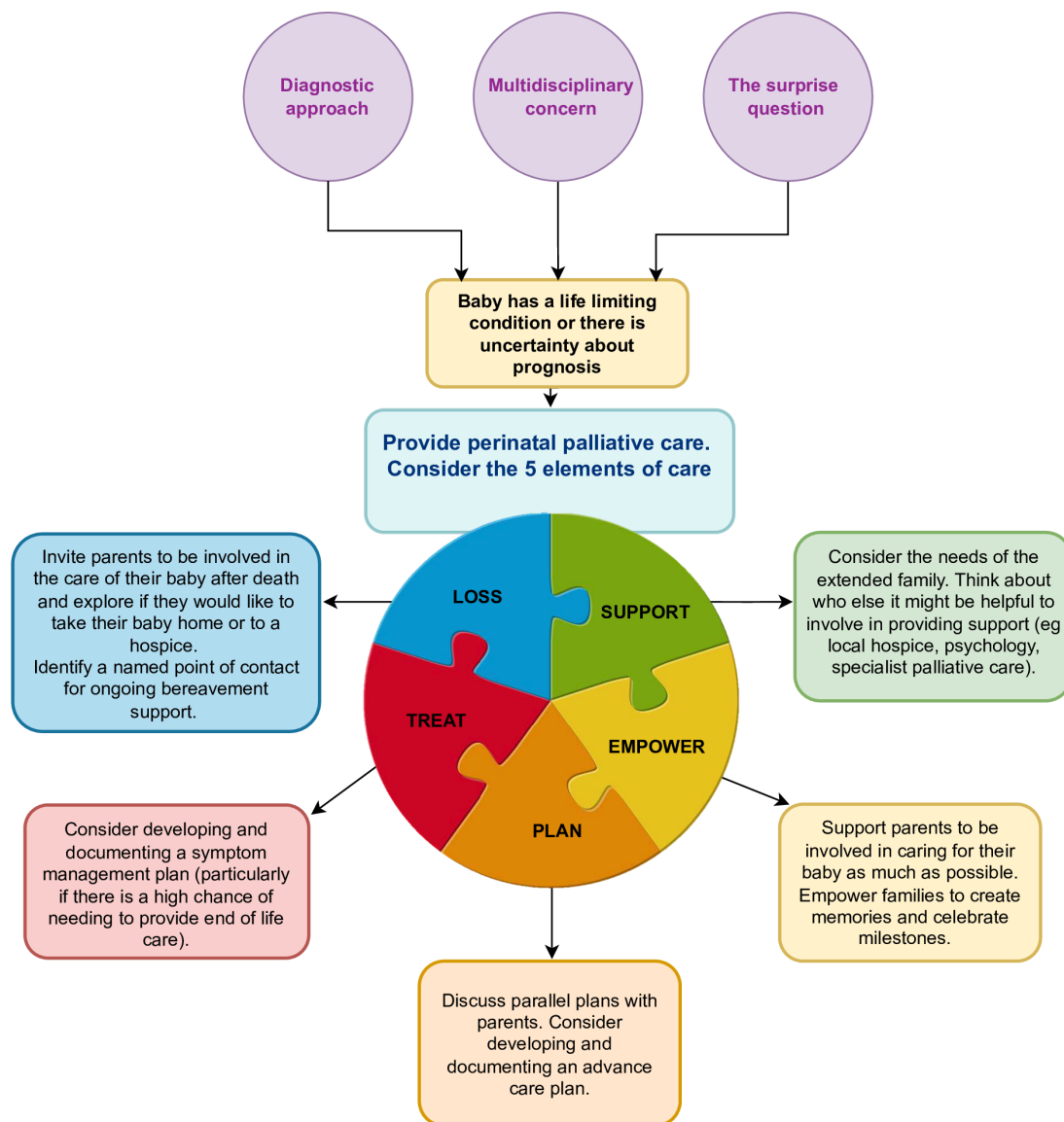


Figure 5 An integrated framework for palliative care in perinatal medicine.

Families who go on to have a subsequent pregnancy should be offered tailored care and support, which takes their previous loss into account (see online supplemental appendix D for information on the Care of Next Infant scheme and The Rainbow Clinic).

DELIVERING PERINATAL PALLIATIVE CARE

Upholding the principles of palliative care is the responsibility of all healthcare professionals who care for babies with life-limiting or life-threatening conditions. Recognition of the need for palliative care may be before birth, soon after birth or further into the postnatal period. The majority of perinatal palliative care (core palliative care) will be delivered by the perinatal team, including medical, midwifery, nursing and allied health professionals (occupational therapy, physiotherapy, speech and language therapy, dieticians), psychology and pharmacy, etc. Usually this will be alongside provision of routine survival-focused care including neonatal intensive care. It may include additional support from perinatal professionals (nurses and doctors) with a special interest and training in perinatal palliative care who lead local services.

The expertise of specialist paediatric palliative care teams may be required to best support some families. Specialist palliative care teams consist of a multidisciplinary team of healthcare professionals with expertise in goal-focused care, complex symptom management, advance care planning and bereavement support. It is important to acknowledge that specialist paediatric palliative care services vary in their availability across the UK, but there are examples of highly effective models that can be used to inform local service development.⁵¹

Decisions of the professional team best placed to support families will be individualised and may change over time. Two-way communication between the perinatal team, providing core palliative care, and the specialist palliative care teams should be encouraged. Not all babies discussed with the specialist palliative care team will require formal referral, but this open dialogue will help ensure families have the best team around them throughout their antenatal and postnatal journeys.

Figure 4 illustrates how core and specialist palliative care services interface to deliver care.

Delivery of palliative care requires investing in dedicated resources including people and services.

People

Important but distinct roles include leadership, provision of elements of palliative care and provision of support following the death of a baby. These roles require funded and dedicated time but may overlap with other roles/processes, for example, mortality leads, complex care, bereavement and/or key worker support (see online supplemental appendix E).

There is a need for identified consultant, midwifery and neonatal nurse lead roles at network level and individual centres who can lead and support service development, education, and coordination of care.

Where perinatal palliative care is being provided (by core or specialist teams), families particularly benefit from continuity of communication and care planning. Units will vary in how they are able to best provide this. While palliative care remains the responsibility of the whole team, consider identifying a named consultant and/or nurse to support the family through the baby's neonatal stay. For babies receiving end of life care, it is important to identify a named point of contact for palliative and bereavement support. In some cases, this may be through a third sector organisation or hospice service, though in other cases, this will be provided by the hospital team.

Other professionals in the multidisciplinary team also provide essential support. Examples include the support of a neonatal pharmacist with palliative care expertise (particularly where medication is required for symptom management at delivery, or at discharge) or speech and language therapy in supporting suck feeds where possible, maximising comfort and pleasure for babies and parents. Training in palliative care should be promoted for all allied health professionals.

Dedicated and funded (commissioned) resources are needed to support care at home of babies with palliative care needs. National Institute for Health and Care Excellence (NICE) guidance suggests that children with life-limiting conditions who are approaching the end of their lives and are being cared for at home should have 24/7 access to children's nurses and advice from a paediatric palliative care consultant.²⁹

Services

There is a need for clear mechanisms to support timely recognition (both before and after birth) of families with palliative care needs. Multi-Disciplinary Team planning will require formal links between specialist palliative care services and neonatal and fetal medicine services. Written guidelines should agree thresholds for formal referral to specialist teams. This may include signposting to local hospice services and other organisations. In addition, there should be mechanisms and forums for regular discussion of patients with the specialist paediatric palliative care team (eg, to provide support for those babies and families receiving core palliative care from the perinatal team).

There should be agreed regional arrangements for transport of babies where end-of-life care is anticipated at home, hospice or local neonatal units. Wherever possible, parents should travel with their baby and the transfer should be facilitated by experienced staff who know the baby and family.

Effective local mechanisms for clinical governance and continuous quality improvement in perinatal palliative care should be established and maintained, including routine collection and analysis of data around babies with palliative care needs, the support provided and key outcomes. It is essential to ensure family involvement in the delivery of services, for example, by providing mechanisms for feedback to inform local service development.

Research recommendations (for researchers, funders, commissioners):

- To support the delivery of best care for babies and families with palliative care needs, there is a need for further clinical, service, quality and research data. Future research should focus on:
 - ⇒ Exploring the impact of receiving palliative care support in the antenatal and perinatal period on the experience of families.
 - ⇒ Evaluating the use of screening tools for identifying patients with palliative care needs before and after birth.
 - ⇒ Evaluating the safety and efficacy of medications for symptom management in the neonatal population characterising symptom management needs at end of life in the neonatal population.
 - ⇒ Developing a routine data set on agreed indicators of perinatal palliative care and agreeing reporting pathways for this data set through national electronic reporting systems.
 - ⇒ Exploring the impact of health inequalities on how families both access and experience perinatal palliative care.
 - ⇒ Generating an evidence base to inform effective education and training programmes and staff support for those working in perinatal palliative care.
 - ⇒ Assessing optimal approaches to communication and shared decision-making with families in the context of perinatal palliative care.
 - ⇒ Understanding the needs of babies who receive perinatal palliative care who survive to discharge.
 - ⇒ Outcomes of babies who receive perinatal palliative care ascertained through observational and record-linkage studies. For survivors, this should include long-term health and education outcomes and self-perceived quality of life.

TRANSITIONS AND PLANNING

For all babies where there is uncertainty about their prognosis, they are likely to experience changing needs and care delivery over time.

For example, some babies may deteriorate and need to transition to end of life care while for others, their outlook may improve such that palliative care is no longer required.

Teams delivering care may shift from obstetric/midwifery to neonatal and later to paediatric. Place of care may shift from local neonatal units to NICU and back again. Babies may transition from the NICU to another intensive care environment, or to a local hospital, to a children's hospice or to home. It can be helpful to anticipate these periods of transition and to ensure that adequate palliative care, across the five key elements of care (see the section Key elements of perinatal palliative care), is available at these times.

It may help to involve both community and specialist palliative care teams from the family's area of residence early when planning for babies with complex issues or where ongoing palliative care support is anticipated. Specialist palliative care teams often have experience in complex discharge planning, and this may be one reason to involve them for advice and support. However, it is important to acknowledge that there can be practical challenges in delivering palliative care in the community due to geographical variation in availability of specialist palliative care.³²

Those delivering perinatal palliative care should make plans for periods of transition. They should provide continuity of care with clear communication of parental understanding,

Guideline

agreed plans and responsibilities. Consider using documented advance care plans where care may be provided by professionals who are not familiar with the baby and family (eg, in the community). Plans should be completed prior to birth or prior to discharge from the neonatal unit and whenever it is anticipated that end of life care and limitations to treatment may be required. There are many elements of a baby's care that it can be important to document. This may include not only resuscitation or interventions in the event of deterioration but also plans for symptom management, place of care and people to be contacted in an emergency. Plans for resuscitation and limitations to treatment should be reviewed regularly as these will often need to change as a baby's circumstances change and evolve (particularly around periods of transition or in exceptional circumstances such as surgery). In some cases, it will be appropriate to document in an advance care plan that a baby remains for full escalation of treatment. Advance care plans should be shared with all professionals involved in care, including the general practitioner (See links in online supplemental appendix D).

It can be very stressful for families to navigate these changes. It is important to assess and support parents' mental and relationship health (eg, drawing on psychology services) especially at times of transition to hospice or home.

SUMMARY

Uncertainty is difficult.

For families, it can be extremely challenging to know how to deal simultaneously with the possibility that their baby will survive but also the possibility that they might die. It is difficult to plan, to make decisions, and to know how to cope. For professionals, it can be difficult to know whether we are doing the right thing for babies, and extremely difficult to know how to communicate with parents. There can be a temptation to avoid talking about uncertainty for this reason.

In this framework, we have acknowledged that such uncertainty is widespread in perinatology, but that it should not be ignored and need not be a barrier to provision of palliative care. Indeed, we have pointed out that some of the elements of palliative care are particularly powerful and important in supporting families and decision-making in the face of uncertainty.

We have presented an *integrated* framework. Figure 5 provides a representation of some of the key elements of the framework. This keeps babies and families at the heart of what we do. It recognises that palliative care encompasses the full spectrum from supportive care offered to babies receiving intensive life-prolonging treatments, to those receiving purely symptom-focused care, those receiving end of life care, and the support of families whose babies have died. It is also integrated in the sense that palliative care is not an alternative to other elements of neonatal and antenatal care. Often it will be provided alongside. Finally, this framework is integrated in the sense that palliative care is not just something provided by specialists. It can and should be embedded within day to day care, delivered by a whole team including obstetricians and midwives, neonatal medical, nursing and allied health professionals, general paediatricians, primary care—supported as needed by specialist palliative care teams.

We are calling then, partly for a philosophical and mindset shift in perinatal care, to embrace the challenge of uncertainty. Our

Workforce recommendations (for commissioners, unit leads, national organisations):

- ⇒ To support the delivery of the perinatal palliative care framework changes in workforce roles and responsibilities will be needed.
- ⇒ Palliative care is the responsibility of the whole perinatal team. Nevertheless, dedicated and funded time for lead roles is essential to provide equitable, consistent, safe and effective Core Perinatal Palliative and Bereavement Care.
- ⇒ Online supplemental appendix E provides detailed recommendations as well as existing examples of medical, nursing and midwifery roles in palliative care and bereavement support. It includes:
 - ⇒ Perinatal palliative care regional and local nursing lead for neonatal intensive care units to provide leadership, management, family support and training.
 - ⇒ Lead neonatal consultant role for palliative and bereavement care.
 - ⇒ Local and regional bereavement midwifery role.
 - ⇒ Administrative support for this team to coordinate documentation and communication of advance care plans, MDT, clinical communications, data collection, reporting.
- ⇒ Dedicated and funded specialist palliative care resources are needed to support neonatal intensive care teams and to support care at home of babies with palliative care needs. Babies with life-limiting conditions who are approaching the end of their lives and are being cared for at home should have 24/7 access to children's nurses and advice from a paediatric palliative care consultant.

framework is aspirational—it sets out what we should be aiming to provide in the care of babies with potentially life-limiting conditions. However, we acknowledge that at present, there is variation in the resources available to achieve this, both within perinatal teams and in specialist palliative care. We have made some specific recommendations to support this shift.

Recommendations for perinatal teams

- ▶ Before and after birth, perinatal health professionals should take active steps to recognise babies who would benefit from palliative care and to integrate this into routine care.
- ▶ Palliative care needs may be recognised through diagnoses, indicating certainly or potentially life-limiting conditions, by a multidisciplinary team who have expressed concern that a baby is at risk of dying, or by screening tools.
- ▶ Tools for identifying babies with palliative care needs before and after birth should be formally evaluated.
- ▶ As part of perinatal palliative care, babies should have five elements of care assessed and provided, including family support, empowerment, parallel planning, symptom management and loss and bereavement care.
- ▶ Perinatal teams and services should develop professional and operational pathways together with their local palliative care services to deliver perinatal palliative care.
- ▶ Where there is a lack of local availability of specialist palliative care, perinatal teams should advocate with commissioners to improve support for babies and families.
- ▶ It is important to collect data around babies with palliative care needs including the support provided and key outcomes.

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Appendix A. Case examples illustrating principles of perinatal palliative care.¹

1. Antenatal palliative care

Sadia and Ali attend for their 20-week anomaly scan and are told that their baby is small and has multiple congenital anomalies including complex congenital heart disease. The picture is suggestive of an underlying chromosomal or genetic diagnosis. Sadia and Ali are committed to continuing the pregnancy and decline invasive antenatal testing.

They are referred to fetal cardiology who confirm the presence of Tetralogy of Fallot with severe pulmonary atresia. This would be amenable to surgery, but the outcome (and whether surgery would be advisable) would potentially depend on gestation at delivery and the genetic diagnosis.

The fetal medicine and neonatal team have an MDT and consider the potential outlook. There is concern that the baby may not survive and given the uncertainty it is agreed the baby would benefit from palliative care.

Does the baby have palliative care needs?



Sadia and Ali meet initially with a neonatologist. The parents’ understanding and priorities are explored. They are hopeful that surgery may be possible for their baby (named Mohammed), but would not wish him to undergo burdensome invasive procedures if he has a severe life-limiting condition. They agree to non-invasive prenatal testing to help with planning. This does not indicate a major trisomy.

A further antenatal visit is planned with the neonatologist to make plans for delivery. The neonatal team discuss the case with the local specialist palliative care (SPC) team with a plan for them to potentially meet the family after birth. An advance perinatal care plan is agreed with parents and included in the mother’s medical record. In the event that the baby is born in good condition, there is a plan for initial

stabilisation, and transfer to the neonatal unit for intravenous prostaglandin infusion and further assessment (including rapid post-natal whole genome sequencing). There is a plan for symptom management and end of life care if baby is born in poor condition.

Sadia goes into labour at 35 weeks gestation. As previously discussed with Sadia and Ali, fetal heart is monitored intermittently (with an explicit plan not to perform emergency caesarean section for fetal compromise). Fetal heart is lost late in the second stage of labour. Mohammed is stillborn. He is given to his parents to hold, and cord bloods are taken for

Consider discussion with specialist palliative care

¹ These case examples are fictional composite cases.

genetic testing (parents decline a post mortem). Parents are offered the option of a cold cot and a chance to stay with Mohammed at the local hospice but elect for early rapid burial. Genetic testing returns 6 weeks later and confirms a severe genetic syndrome. Bereavement support is provided by the local bereavement midwives.

2. Perinatal palliative care

Claire develops pre-eclampsia at 24 weeks and 3 days gestation. This is her second pregnancy (previous normal delivery at term), and her female fetus is growth restricted (estimated fetal weight 440g) with reversed end diastolic flow.

Claire meets with a neonatologist who discusses with her the baby's outlook if delivery occurs soon, and Claire and her partner Elliot's understanding and priorities. Claire receives antenatal steroids and there is a plan for survival-focused care at delivery. The neonatologist discusses with Claire the possibility of her baby dying despite intensive care, and the need for further discussions and review after delivery.

Baby Leah is born two days later by caesarean section (birth weight 454g). She is intubated and taken to the intensive care unit, where she responds well to initial stabilisation.

While Leah is currently receiving full intensive care, the neonatal team identify that given her gestation and birth weight she remains at significant risk of dying prior to discharge, and consequently has palliative care needs. The consultant who was present at the time of

Does the baby have palliative care needs?



delivery is identified as providing continuity support. She considers the elements of perinatal palliative care and meets with Claire and Elliot together with a neonatal nurse who has received training in family support and palliative care. They discuss potential uncertainty and challenges ahead. Leah's symptoms appear currently well controlled. The parents have a large close family to support them but are offered support from psychology, chaplaincy, and outreach from the local hospice to support Leah's older sibling. The

consultant agrees with Claire and Elliot that it is appropriate for Leah to continue to receive intensive care and full resuscitation (if required), with regular consultant review. The family's priorities, hopes and fears are documented in Leah's medical record.

At 2 weeks of age, Leah has a life-threatening deterioration with gram negative sepsis and necrotising enterocolitis. She is critically ill, and further conversations with Claire and Elliot are held about the serious chance of her dying from this illness. They remain clear that they would like all measures to be taken to save their daughter. The on-call consultant is able to draw on previously documented conversations and planning. He has further discussion about the family's wishes in the event that she deteriorates further, or survival is not possible. The parents agree that if Leah's heart were to stop, they would not wish for cardiac compressions. Support from on call chaplaincy is arranged. Leah has a laparotomy and has resection of most of her small bowel (15cm remaining).

Post-operatively, Leah is gravely ill for several days, and then stabilises. Given recent events, and that she now has short gut

Consider discussion with specialist palliative care

syndrome, the neonatal team refer to the local specialist palliative care (SPC) team for additional ongoing support with symptom management, family support and parallel planning.

Leah has a long stay in the neonatal intensive care unit with multiple complications. The named consultant and nurse, together with the palliative care team support her and her parents over that time. She remains dependent on partial parenteral nutrition. Leah has a formal advance care plan written and agreed at the time of transfer to the paediatric wards at 4 weeks post term. Her advance care plan includes a plan for full resuscitation in the event of deterioration.

Appendix B. Suggestions for discussing palliative care with families

Communication with families about palliative care, parallel planning, and end of life care is a key skill for perinatal professionals. It should be sensitive to the needs and cultural background of families. In many cases, it will take place over a number of conversations. NB The prompts below are suggestions and should not be seen as a template or a script.

Five key questions (54,55)

1. Tell me about your baby (Tell me about your family)
2. What have you been told about your baby's condition?
3. What are your hopes for your baby? What is most important for you and your family'?
4. What are your fears for your baby? What is worrying you the most?
5. What do I need to know about you and your family to help you best?

Introducing palliative care (54)

We have discussed some of the uncertainty of your baby's condition. That uncertainty is often very difficult.

For our sicker babies and those whose future is uncertain, we try to provide extra support for both baby and parents.

We work hard to ensure that baby's symptoms are well controlled, that we have carefully thought about and made plans for the future if possible, and that we are giving the family as much help as we can at a difficult time.

Sometimes we involve our colleagues from the palliative care team. Children's palliative care is life-long supportive and holistic care (that means that it covers a wide range of different areas). The palliative care team have special expertise in looking after children and their families when we have a worry that the child may not survive.

Some families find the term scary, but actually 'palliative care' is just about providing the best possible comfort and quality of life for a baby, however long they are with us, whether that is a short time, or even for many years.

It is normal for us to refer families to palliative care services for extra support in this type of situation.

I have a wider team that I work with to make sure you have the care that you and your baby need, when and where you need it. Some families have referred to this as 'a community of support'.

Talking about uncertainty

Palliative care is about helping to make your child's life as good as it can be.

When we aren't sure what is going to happen, some parents find it helpful to hope for the best as well as make plans for the worst/plans for the rest.

It can be helpful to talk about what might happen, as well as what we think is most likely.

In this situation (eg when the breathing tube is removed), it is hard to know what will happen next. I don't know how long you will have with (your son/daughter). It might be only a very short time, but sometimes it is longer. Sometimes babies surprise us.

Because we are not sure exactly what is going to happen, it can be important for us to have several different plans. We might need a 'plan A' for what we think is most likely, but then a 'plan B' in case that doesn't happen. Sometimes we need a plan C and D as well. How does that sound?

How to start conversations about spirituality and cultural considerations (56)

Some questions which may be helpful to ask parents with whom you are working (it is important to document the answers and hand this information over between professionals):

- Is there anything related to your culture or religion that we should know about so that we can care for you and your baby?
- Spirituality and faith is important to a number of the families that I meet. Do you have beliefs that you would like those caring for you and your baby to know about?
- How do those beliefs help you cope with difficult times in your life?
- Do other people in your family share the same beliefs?
- Is there anything we can do that would help you feel connected to your faith community? Is there anyone you would like us to call?
- Would it help to talk to a chaplain about how are feeling?
- How can we support you to find the strength you need?

- When life is particularly challenging, different sources of support can be helpful for different people. What about you? Is there anything that you need that could be of comfort or support to you at this time?

Cultural link workers, if available, can be invaluable support for continuity and culturally sensitive care.

Appendix C. Certainly and potentially life-limiting conditions identified in the perinatal period (5)

This is not an exhaustive list and there may be many other diagnoses in which there is uncertainty about the expected outcome and delivering palliative care is appropriate. See main text for alternative ways in which babies with palliative care needs may be recognised.

PREGNANCY RELATED

- Very severe intra-uterine growth restriction
- Prolonged preterm rupture of membranes from early gestation with oligohydramnios/anhydramnios

PREMATURITY RELATED CONDITIONS

- “High risk or Extremely high risk” Extremely preterm delivery e.g., preterm infants at 22-23 weeks gestation (See BAPM Framework for definition of High Risk and Extremely High Risk (13))
- Extremely preterm infants with severe complications e.g., severe necrotising enterocolitis, intraventricular haemorrhage, cystic periventricular leukomalacia, severe chronic lung disease

MULTI-SYSTEM

- Newborn infants with organ failure requiring escalation to extra-corporeal membrane oxygenation or dialysis or solid organ transplantation
- Severe congenital skin disorder eg Epidermolysis bullosa, Harlequin fetus
- Severe hydrops fetalis
- Multiple severe congenital abnormalities (that may or may not be treatable) in the absence of a clear diagnosis

GASTROINTESTINAL

- Babies with short gut following bowel resection or long-term dependence on parenteral nutrition

NEUROLOGICAL/MUSCULAR

- Newborn infants with brain injury and high risk of severe disability e.g., infants with severe (Sarnat III) hypoxic-ischaemic encephalopathy
- Neonatal or fetal onset neuromuscular disorder e.g., myotonic dystrophy, congenital myopathy, spinal muscular atrophy
- Severe brain abnormality eg Anencephaly, Craniorachischisis, Hydranencephaly, Holoprosencephaly, Iniencephaly, Lissencephaly
- Vein of Galen malformation

GENETIC/ CHROMOSOMAL

- Severe chromosomal abnormality eg Trisomy 13 and 18 (including mosaicism), triploidy
- Post-natal exome sequencing indicates a causative diagnosis that has the potential to lead to death in early childhood.

CARDIAC

- Severe congenital cardiac conditions that may not be amenable to surgery, or only with severe morbidity e.g., single ventricle conditions
- Severe fetal cardiomyopathy

AIRWAY/RESPIRATORY

- Severe lung or airway abnormality (eg Alveolar capillary dysplasia, laryngeal or tracheal atresia)
- Newborns where there is a question about providing tracheostomy for long-term ventilation
- Severe congenital diaphragmatic hernia

RENAL

- Bilateral Renal agenesis
- Other severe disorders of renal system eg severe multicystic dysplastic kidneys and oligohydramnios, urethral or bladder agenesis

SKELETAL

- Severe skeletal dysplasia (including osteogenesis imperfecta)
- Arthrogryposis with confirmed severe neuromuscular disorder

Appendix D Useful resources

- Caring for your baby when the future is uncertain: an information booklet for parents about perinatal palliative care (Together for Short Lives/BLISS) <https://www.togetherforshortlives.org.uk/get-support/supporting-you/family-resources/caring-for-your-baby-when-the-future-is-uncertain/>
- Child and Young Person's Advance Care Plan (CYACP) Collaborative <http://cypacp.uk>
Contains templates for writing an advance care plan both before and after birth.
(Other advance care plans are used for children in different parts of the country; clinicians should use plans that are recognised/endorsed locally)
- National Bereavement Care pathway <https://www.nbcpathway.org.uk>
- Together for Short Lives <https://www.togetherforshortlives.org.uk>
- Bliss <https://www.bliss.org.uk>
- Antenatal Results and Choices <https://www.arc-uk.org>
- SANDS <https://www.sands.org.uk>
- Child Bereavement UK www.childbereavementuk.org
- Association of Paediatric Palliative Medicine Formulary <https://www.appm.org.uk/formulary/>
- Child Death Helpline <https://www.childdeathhelpline.org.uk>
- HEARD Communications Toolkit: How to talk about children's palliative care https://heard.org.uk/wp-content/uploads/2023/01/Heard_How-to-talk-about-childrens-Palliative-Care_draft_v2.pdf
- BAPM Framework for Practice: Lactation and Loss <https://www.bapm.org/resources/lactation-and-loss-management-of-lactation-following-the-death-of-a-baby>
- Family Integrated Care: A BAPM Framework for Practice <https://www.bapm.org/resources/ficare-framework-for-practice>
- The Lullaby Trust: Care of Next Infant <https://www.lullabytrust.org.uk/bereavement-support/how-we-can-support-you/our-care-of-next-infant-scheme/>

- Tommy's Rainbow Clinic: Improving maternity care following a previous loss <https://www.tommys.org/our-research/our-research-projects/stillbirth-research/rainbow-clinic-improving-maternity-care>
- NHS Organ Donation <https://www.organdonation.nhs.uk>
- Twins Trust <https://twinstrust.org>
- Footprints Baby Loss <https://www.footprintsbabyloss.org>
- The Butterfly Project <https://www.neonatalbutterflyproject.org>

Appendix E Proposed Perinatal Workforce Structure

As emphasised in the framework, palliative care is the responsibility of the whole perinatal team. Nevertheless, dedicated and funded time for lead roles is essential to provide equitable, consistent, safe and effective Core perinatal Palliative and Bereavement Care. To assist in business case preparation and planning, we provide below summary recommendations, an outline of the expected workload in a single high-volume centre, and examples of currently funded palliative/bereavement care roles. Workload estimates are based on existing models of care (Table E.3) as well as work from the National ODN Education and Workforce Leads Group. (NB We refer to specialist palliative care below; however, detailed workforce planning for specialist palliative care services is outside the scope of this framework).

Table E.1 Summary recommendation

Consultants	
Neonatal Consultants – Palliative and bereavement lead role	Dependent on size and type of unit, number of admissions/intensive care bed days etc 1.0 – 2.0 x PA per week for NICUs ~0.5 x PA per week for LNUs/SCs
Nursing & Midwifery Specialist Roles	Dependent on - Number of care days delivered - Number of sites covered
Neonatal Palliative Care Nurse Regional role for each of 10 regions/Network/ODNs	1 .0 WTE Band 8 per region/Network/ODN (Recommendations by the National ODN Education and Workforce Leads Group)
Neonatal Complex, Palliative & Bereavement Care Nurse Neonatal Nurse roles on the Neonatal Unit for each Neonatal Unit	e.g. NICUs 1.0 WTE Band 7 minimum (dependent on number of delivered care days and number of sites covered) LNUs/SCs 0.1/0.2 WTE Band 7 (suggested recommendation, 0.1 WTE per 1000 delivered care days (minimum 0.2WTE)
Bereavement Midwives- Regional roles (currently in planning stages)	1.0 WTE Band 8 per region
Bereavement Midwives- each Maternity Unit	1.0 WTE Band 7 for each 2,500 deliveries Also dependent on how many sites cover and how many additional departments covered, such as ED, Gynaecology, EPU

Example of workload in a busy level 3 NICU (4000 Intensive care bed days/year, co-located regional fetal medicine and surgery):
Average 40 deaths per year (3/month)

Expected ~80 admissions per year (6/month) meeting previous BAPM categories for palliative care [based on Harnden 2023] – (NB Number of babies recognised as having palliative care needs according to revised framework is anticipated to be greater than this, since the revised framework acknowledges the potential value of a palliative approach in a wider range of cases, including where prognosis is uncertain.)

Average 12 antenatal palliative care consultations per year (1/month – supporting regional antenatal palliative care)

Recommended medical consultant PAs: 2+PA per week (potentially divided among several individuals)

Recommended nursing lead role: 1 WTE Band 7

- Lead medical and nursing dedicated time to include:
- Education and training for nursing and medical teams
 - Emotional and practical support for families
 - weekly meeting (together with on-service consultants, psychology/mental health support and FiCare team to support core palliative care)
 - weekly meeting with fetal medicine
 - regular meeting with specialist palliative care
 - MDTs to support transition and advance care planning
 - joint meetings with PMRT – review of care provision, education and training for nursing and medical teams
 - Report of service delivery and outcomes
 - Participating in network/national service and professional meetings

Table E.2 Recommendations for nursing and midwifery specialist roles

Nursing & Midwifery Specialist Roles - Dependent on number of care days delivered and number of sites covered	(Recommendations by the National ODN Education and Workforce Leads Group)
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REGIONAL Neonatal Palliative Care Nurse Regional role for each of 10 regions/Network/ODNs 1 .0 WTE Band 8 per region/Network/ODN • Provide professional and strategic leadership across the region on the development and operational delivery of safe effective and equitable perinatal palliative care services through working with local, regional and national teams. This should include working with specialist palliative care teams, hospice and 3rd sector organisations • Provide leadership on the governance, assurance & surveillance of delivery of national guidance, standards, best practice, workforce development, training needs and delivery, patient and staff feedback, quality safety performance indicators. • Engage in MDT leadership with other aligned regional and network leads; bereavement, FI care, network, to ensure efficiency of integrated pathways • Provide oversight of perinatal palliative care team involvement in perinatal mortality review process • Provide leadership on education and training programmes to support consistent best practice • Oversee access to restorative clinical supervision is for lead nurses supported by PNA’s and designated psychologists • No direct patient care, but work closely with all lead nurses across the region including on site presence at all of the regional units	LOCAL Neonatal Complex, Palliative & Bereavement Care Nurse Neonatal Nurse roles on the Neonatal Unit for each Neonatal Unit e.g NICUs 1.0 WTE Band 7 minimum (dependent on number of delivered care days and number of sites covered) LNU 0.1/0.2 WTE Band 7 (suggested recommendation, 0.1 WTE per 1000 delivered care days (minimum 0.2WTE) • Work with the regional/network lead nurse to deliver perinatal palliative care as per regional and national guidance and governance • Work with the perinatal palliative care team including neonatal. Midwifery and obstetric leads to deliver the service • Provide clinical leadership and support for the team in delivering perinatal palliative care • Available to provide leadership and continuity when staff need additional support • Work with specialist paediatric team, bereavement and FI care teams to ensure integrated efficient care • Lead on education and training that has been developed by the regional/ network team • Point of contact for the perinatal mortality review team and ensure input into all reviews • Actively seek, monitor & evaluate feedback from parents and staff • Lead regular reflective practice for the neonatal team, including PNA’s • Direct patient care when leading perinatal palliative care usually for more complex cases
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Aligned with the 3 year delivery plan & NHS Workforce Plan: *‘the **3 year delivery plan** will make maternity & neonatal care safer, more personalised & equitable for women, babies and families..... ‘**compassionate and high quality care** for bereaved families’*

Specialist palliative care

A specialist multidisciplinary team should include at a minimum: a consultant in paediatric palliative medicine, a clinical nurse specialist (Band 8) with expertise in paediatric palliative care, a paediatric pharmacist with expertise in paediatric palliative care and experts in family support, including provision of psychosocial support in the context of end of life care and bereavement. Specialist paediatric palliative care teams team need to be able to provide the workforce to support children and young people on a 24/7 basis. Provision should be made for medical and nursing cover across all clinical settings to allow assessment, advice and active management seven days a week, and 24-hour telephone advice. This may require a collaborative arrangement between a number of service providers and joint commissioning with the aim of providing 24-hour access to specialist advice from a consultant in palliative medicine, including face-to-face assessment where necessary.

Table E.3 Existing Models of Specialist Perinatal Palliative & Bereavement Care Roles

	Trust & Unit	Band	WTE /PA
Medical			
Perinatal palliative care	Edinburgh/NHS Lothian	Cons	1 PA (shared)
Perinatal palliative care and bereavement	Liverpool Women’s Hospital	Cons	1.5 PA 1 PA for palliative care 0.5 PA for bereavement
Consultant neonatologist and Hospice Doctor	Leeds	Cons	1PA (4 hours) per week for hospice (worked as 2 full days per month), 10PA (full time) for Leeds NICU
Nursing and midwifery			

Regional Neonatal Palliative Care Specialist Nurse (Transition & Outreach)	South West ODN	8	1.0 WTE
Neonatal Complex, Palliative & Bereavement Care Specialist Nurse	Chelsea and Westminster Hospital London NICU	7	1.0 WTE
Neonatal Complex, Palliative & Bereavement Care Specialist Nurse	Derby (WM) & Burton (EM) (LNU & SC) Across 2 sites & 2 x ODNs	7	0.6 WTE Across 2 sites
Bereavement Nurse (job share)	Leeds	7	1.2 WTE
Snowdrop Team Neonatal Nurse Bereavement Lead and Lead Bereavement Midwife (shared role)	Bristol		1.6 WTE Plus Band 6 0.5 WTE 2 yr secondment
Regional Bereavement Midwife	(currently in development)	8	1.0 WTE
Bereavement Midwife	Various	7	1.0 WTE
Children’s Hospice Roles			
Perinatal Palliative Care Nurse Consultant	Claire House Children’s Hospice	8	1.0 WTE
Perinatal Midwife	Forget Me Not Children’s Hospice	7	1.0 WTE

