

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.

PREFACE

When the BAPM published “Palliative Care (Supportive and End of Life Care): A Framework for Clinical Practice in Perinatal Medicine” in 2010 this was a major step forward in recognising the important role that perinatal specialists play in caring for babies with life-limiting conditions. It provided a benchmark for what good parallel care planning and end of life care should look like and acknowledged the need for specific individualised support for parents and families.

In the 14 years since then, paediatric palliative care services have become incorporated into neonatal, and more recently antenatal, services. Increasingly there has been a recognition that employing a fully holistic and interdisciplinary model of palliative care into perinatal care has important benefits for babies and families, as well as the health care professionals caring for them. Over the same period, paediatric palliative care in the UK has developed significantly, with a growing number of specialist palliative care teams who work closely with colleagues in women’s and child health. Research in perinatal palliative care has also expanded and laid the ground for this framework.

This new palliative care framework has been developed as a joint venture in conjunction with the Association of Paediatric Palliative Medicine (APPM). In this version, we move away from a list of specific conditions, and instead propose a model that recognises the inherent uncertainty present in the care journey for so many babies and their families. The document outlines an integrated framework of perinatal palliative care which is appropriate for all instances where there exists uncertainty about a baby’s outcome. This model emphasises that palliative care is not synonymous with end-of-life care but rather represents an active and total approach to care which can be delivered from the point of diagnosis and alongside treatments directed at survival. It includes symptom management and parallel planning, but also empowering parents to be involved in the care of their baby and in decisions. It also highlights how palliative care is very much ‘everyone’s business’ and can and should be delivered by existing perinatal teams with support from community and specialist services where required. Many of the elements of palliative care overlap with elements of Family Integrated Care and are very familiar to perinatal teams. Other elements are less familiar or have traditionally not been contemplated unless, or until, babies are receiving end of life care.

Acknowledging uncertainty and discussing palliative care can be challenging for perinatal teams. We recognise that sometimes using the terminology “palliative” can itself be a barrier for both parents and health care professionals. This revised document offers a framework which is aligned with contemporary paediatric palliative care, by clearly naming the care for what it is. By outlining the breadth and scope of palliative care this document aims to increase professional confidence in using the term and to highlight the many excellent components of palliative care that are already routinely being delivered by perinatal teams.

Scope

The framework is intended as supportive guidance for all healthcare professionals working in perinatal medicine across antenatal and neonatal services to help inform the development of integrated palliative care pathways at a local level.

The focus is *perinatal*: on provision of care for babies with potentially life-limiting conditions and their families, before and after birth. However, parts of the framework (particularly relating to babies transitioning to community care) will overlap with paediatric palliative care.

The framework is not a detailed guideline for how to practice palliative care (for example how to manage symptoms or develop advance care plans) and does not replace specialist expertise. It does not include detailed guidance for medical, nursing or allied health professionals in how to provide important components of care. It sets out recommendations for both workforce and necessary research.

Some practical suggestions are included in the Appendices. Appendix A includes two case studies to illustrate how the integrated approach might be provided. Appendix B includes suggestions for helpful language or questions to use in communicating with families.

I. 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 prematurely [4] 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 whilst 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 health care 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 BAPM and APPM, taking into 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 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 survival [14] 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.

II. 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.

Firstly, 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.

Secondly, 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 (sometimes misleadingly called “Active Treatment”).¹

Thirdly, 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 section V).

¹ This is an imperfect term since palliative care involves an active approach and many active interventions.

III. RECOGNISING BABIES WHO MAY BENEFIT FROM PALLIATIVE CARE

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

1. 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 [20]. Some babies will exceed expectations and many babies who have palliative care needs will survive to discharge [5].

- “High Risk” Extremely Premature infants eg 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 eg Sarnat III hypoxic-ischaemic encephalopathy, severe intra-ventricular haemorrhage
- Post-natal exome sequencing indicates diagnosis with the potential to lead to death in early childhood.

Box 1: Examples of potentially life-limiting conditions. See Appendix C for a longer list of conditions.

2. 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 to further discussion and formal consideration of a baby's potential palliative care needs.

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 [21,22].

“I knew the doctors were worried about something and not sure what to say. I just wanted to know what it was and be involved, I didn't need them to have all the answers. Not knowing for weeks and weeks was so worrying.”

3. 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'[23–25]. "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 multi-disciplinary 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 health care professionals in a way that effectively communicates prognostic information but that also responds to the emotions generated by the conversation [26] . 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 [27]. See Appendix B for suggestions about discussing palliative care with families.

IV. KEY ELEMENTS OF PERINATAL PALLIATIVE CARE

For many babies, palliative care will (at least initially) be an *addition* to other elements of care and won't 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.

1. 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 [28,29]. 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 e.g., 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 [26,30].

"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.

2. 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 identity as a parent recognised [31]. Empowering parents to be a central part of Family Integrated Care for their baby [32], 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.

Whilst 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).

3. 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 [33,34]. Planning for the future at times of great uncertainty has been shown to be comforting for both parents and children [35–37].

Parallel planning refers to the process of planning for life while also planning for the possibility of deterioration or death [38]. It allows families and professionals to prepare for a range of possible outcomes in settings of uncertainty [39]. 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 section VII, and links in Appendix D). Specialist palliative care teams can provide support for parallel and advance care planning.

4. 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 [40–43]. 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.

5. 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 [44].

After the death of a baby, parents and the extended family will require bereavement support [45]. Ongoing contact with the staff who cared for their child can be a great source of support to families [46]. Specialist psychology support may be accessed via maternal mental health services, neonatal units, specialist paediatric palliative care teams and/or children's hospices [47].

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 [48]. Consideration should be given to providing lactation care, drawing on the support of the local infant feeding team. This includes option of milk donation as well as anticipatory guidance around lactation suppression, for all mothers facing the possibility of a stillbirth or neonatal death [49,50].

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 [51].

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 doesn't die, but has experienced palliative care needs, collecting feedback from families is essential to service improvement.

In situations where a family experience 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 Appendix D for information resources on supporting bereavement from a multiple birth perspective.

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

V. 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 [52].

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 journey.

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 eg mortality leads, complex care, bereavement and/or key worker support (see 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. 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. MDT 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.

VI. 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 whilst 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 section IV), 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 [53].

Those delivering perinatal palliative care should make plans for periods of transition. They should provide continuity of care with clear communication of parental understanding, 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 resuscitation or interventions in the event of deterioration, but can also include 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 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 (for example drawing on psychology services) especially at times of transition to hospice or home.

VII. 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 focussed 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 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 multi-disciplinary 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.

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

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.
- Appendix E provides detailed recommendations, as well as existing examples of medical, nursing and midwifery roles in palliative care and bereavement support. It includes:
 - o Perinatal palliative care regional and local nursing lead for neonatal intensive care units to provide leadership, management, family support and training
 - o Lead neonatal consultant role for palliative and bereavement care
 - o Local and regional bereavement midwifery role
 - o 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

Figure legends:

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 Hawley [19])

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

Figure 3: Elements of palliative care

Figure 4: Interface of Services Delivering Perinatal Palliative Care

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

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DW and SB contributed equally to this paper. DW and SB drafted the framework and appendices, subsequently editing the manuscript in response to consultation and feedback, compiled the figures and approved the final manuscript. AM and EM chaired the Working Group and contributed significantly to the drafting of the article and appendices and subsequent edits and approved the final manuscript. All collaborators attended at least one meeting of the Working Group and contributed to the writing and editing of the Framework for Practice and appendices. All collaborators approved the final manuscript.

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Competing interests:

None declared.

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