



British Association of
Perinatal Medicine



Recognising Uncertainty: An integrated framework for palliative care in perinatal medicine

A DRAFT Framework for Practice

April 2024

Developed in
Partnership with

Association for
Paediatric
Palliative
Medicine

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Executive Summary

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 managing 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.

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 cases 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 cure. It also highlights how palliative care is very much 'everyone's business' and can be delivered by existing perinatal teams with support from community and specialist services where required.

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

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.

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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⁽¹⁻³⁾.

However, owing to a range of factors, the number of fetuses and babies who are now eligible for palliative care is increasing. The largest increase in the prevalence of children with life-limiting or life-threatening conditions over recent years has been in infants under the age of 1 year⁽⁴⁾. 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⁽⁵⁾. Furthermore, success in acute stabilisation of critically ill newborns born extremely prematurely⁽⁶⁾ 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 impairments linked to the underlying disease and its treatments.

Perinatal teams have for some time recognised and embraced the importance of palliative care for fetuses and newborn infants with terminal illness⁽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. We also undertook a review of available palliative care guidelines within the UK.

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⁽⁹⁾, 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 or cure⁽¹⁰⁾ and that palliative care is compatible with simultaneously honouring hope⁽¹¹⁾.

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 children 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 child’s family⁽¹²⁾. Palliative care is not the same as end-of-life care (the care of a baby in the dying phase), though it includes end-of-life care as and when that is appropriate.

The term **‘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^(13,14). 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.

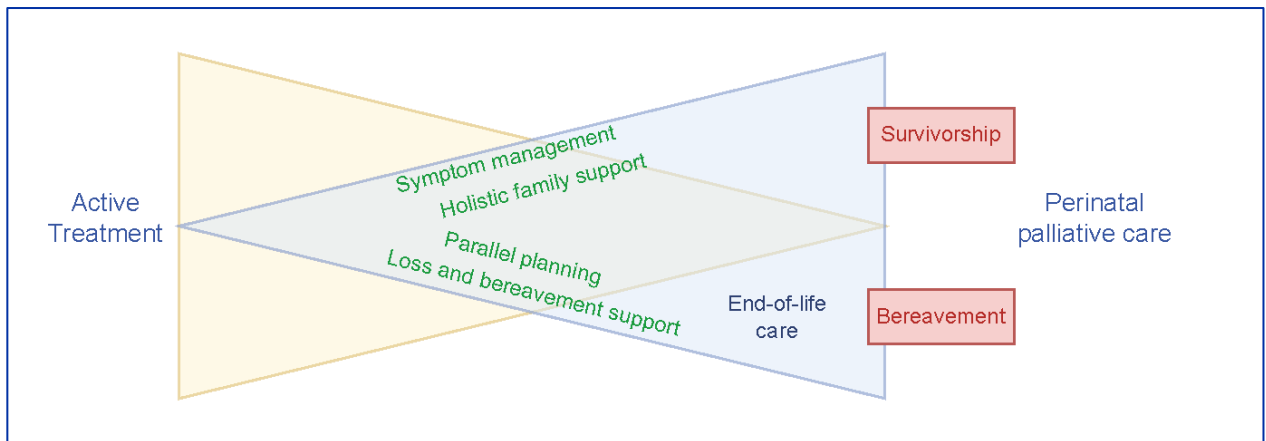
Firstly, we encourage teams to use palliative care as an umbrella term which encompasses the full spectrum of supportive care and end of life care. This broader definition of palliative care includes a common approach to the holistic care of fetuses and babies (and their families) with both certain and potentially life-limiting conditions (Figure 1). This includes many babies who are not actively dying, 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 so-called “active treatment”¹.

Thirdly, palliative care will 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 the support of specialist palliative care teams as required (see page 13).

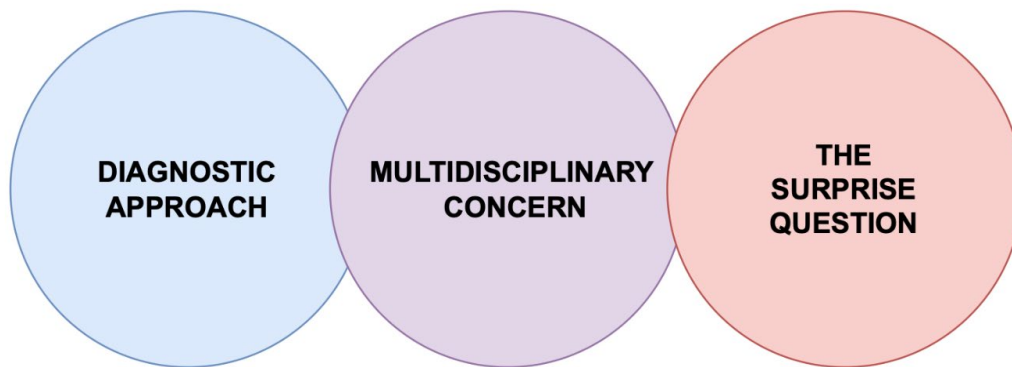
¹ This is an imperfect term since palliative care involves an active approach and many ‘active’ interventions.

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 active treatment. (Adapted from the Bow Tie model by Philippa Hawley⁽¹⁵⁾).

Identifying babies who may benefit from palliative care



Here are three different ways of identifying babies who may benefit from palliative care:

The Diagnostic approach

Babies or fetuses may be diagnosed with a condition that is certainly or potentially life-limiting⁽¹⁶⁾. Provision of palliative care following the diagnosis of certain life-limiting conditions such as anencephaly or trisomy 13 is uncontroversial.

Babies may also be identified 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. Some babies will exceed expectations and many babies who have palliative care needs will survive to discharge⁽¹⁶⁾.

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

- '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
- Fetuses/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.

Multidisciplinary team and family perspective

Even in the absence of a specific diagnosis, babies may be at risk of dying⁽¹⁶⁾. Uncertainty or concern expressed by medical professionals, by nursing staff, by allied health professionals or by parents should prompt discussion and consideration.

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^(17,18). It can be particularly helpful to encourage nursing staff who are working at the cotside to share their viewpoints with the wider team.

“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.”

Parent experience

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’^(19–21). “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 ward rounds 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 patients with palliative care needs before and after birth.)

Communicating with families

Once a baby has been identified 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. 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 worries, and what matters most to them as the trajectory of the illness becomes clear⁽²²⁾. See Appendix B for suggestions about discussing palliative care with families.

Key elements of perinatal palliative care



For many babies and fetuses, palliative care will (at least initially) be an *addition* to other elements of care rather than a change or a reorientation of care.

There are five key elements in the provision of perinatal palliative care as represented by the diagram above. The needs of babies and families will differ and will likely change over time, needing regular review.

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 complex or refractory cases^(23–25).

Specialist palliative care teams may be able to advise on alternative and novel approaches to management, particularly when symptoms are refractory to standard treatment⁽²⁶⁾.

SUPPORT: Holistic family support

Having a baby with a certain 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. The help of additional professionals may be needed e.g., social work, family support workers, chaplaincy. Many children's hospices will offer specialist sibling support sessions and activities^(29,30).

"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.

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. 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^(31,32).

Planning for the future at times of great uncertainty has been shown to be comforting for both parents and children⁽³³⁻³⁵⁾.

Parallel planning refers to the process of planning for life while also planning for the possibility of deterioration or death⁽³⁶⁾. It allows families and professionals to prepare for a range of possible outcomes in settings of uncertainty⁽³⁷⁾. 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 (see link to the Child and Young Person's Advance Care Plan collaborative in Appendix D). Specialist palliative care teams can provide support for parallel and advance care planning.

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⁽³⁸⁾. Empowering parents to participate in parenting tasks (such as feeding, bathing and dressing) and facilitating physical contact with their baby where possible is of paramount importance. 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 around a child'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.

CARE: Loss and Bereavement

All families of babies with palliative care needs will experience loss. Even if the baby recovers, parents potentially experience loss of a normal pregnancy/birth experience, anticipatory loss (at the possibility or expectation that their baby may die), and trauma relating to experiences during birth or in NICU⁽³⁹⁾.

After the death of a baby, parents and the extended family will require bereavement support. Ongoing contact with the staff who cared for their child can be a great source of support to families⁽⁴⁰⁾. Specialist psychology support may be accessed via neonatal units, specialist paediatric palliative care teams and/or children's hospices⁽⁴¹⁾.

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.

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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⁽⁴²⁾. Consideration should be given to providing lactation care, including anticipatory guidance around lactation suppression, for all mothers facing the possibility of a stillbirth or neonatal death⁽⁴³⁾.

Although neonatal organ donation is currently rare, cases where there may be potential for neonatal tissue and/or organ donation should trigger early discussion with the local Specialist Nurses in Organ Donation⁽⁴⁴⁾.

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.

Delivering perinatal palliative care

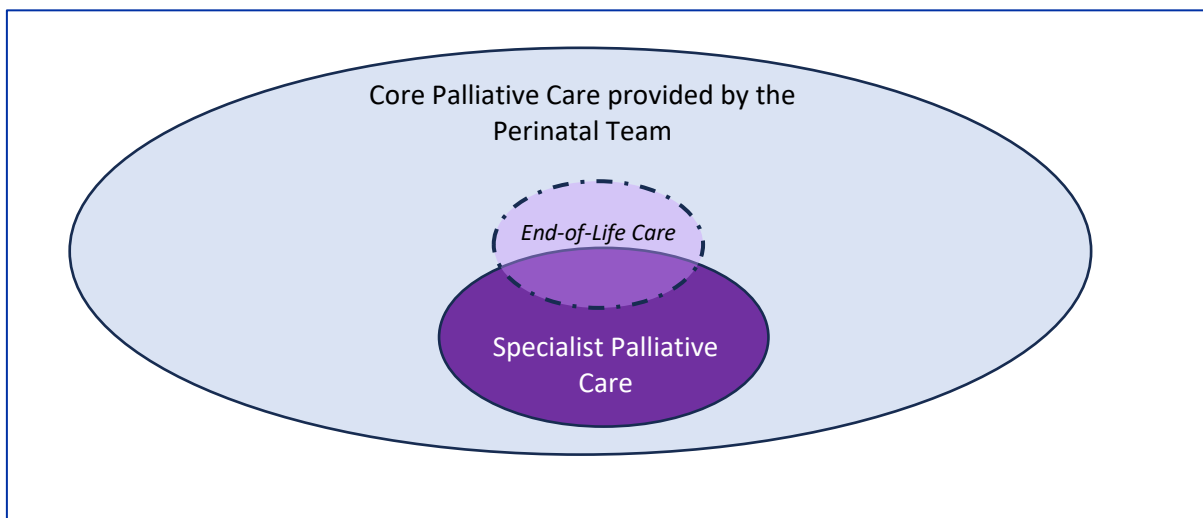
Upholding the principles of palliative care is the responsibility of all healthcare professionals who care for fetuses/babies with life-limiting or life-threatening conditions. Recognition of the need for palliative care may be before birth, soon after birth or further into the postnatal period. The majority of perinatal palliative care (core palliative care) will be delivered by the perinatal team, which may include medical, midwifery, nursing and allied health professionals, usually alongside offering other care including neonatal intensive care. This may include additional support from perinatal professionals (nurses and doctors) with a special interest and training in perinatal palliative care.

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. Specialist paediatric palliative care services are not yet available in all areas of the UK and there are regional variations in both the models of service delivery and thresholds for formal referral⁽⁴⁵⁾.

Decisions of the professional team best placed to support families will be individualised and may change over time. Processes to facilitate two-way communication between the perinatal team, providing core palliative care, and the specialist palliative care teams should support timely identification of families who may benefit from specialist palliative care. 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.

The diagram below illustrates how core and specialist palliative care services interface to deliver care.

Figure 2: Interface of Services Delivering Perinatal Palliative Care



Jointly agreed local pathways should be developed to support the interface between teams providing core and specialist palliative care, this may include additional guidance on links with local hospice services and other third sector organisations. Agreed pathways will vary but should aim to include:

- Clear mechanisms to support timely identification and MDT planning for families with

palliative care needs identified antenatally, including formalising links between specialist palliative care services and fetal medicine services.

- Written guidelines should be agreed defining thresholds for formal referral to specialist teams. This may include signposting to local hospice services and other charity organisations.
- Agreed forums through which cases can be discussed with the specialist paediatric palliative care team regularly.
- Identified consultant, midwifery and neonatal nurse palliative care champions in each centre, with appropriate time to support these roles through job planning processes where possible, with key responsibility to:
 - act as named contacts for core palliative care queries and concerns for both perinatal professionals and families
 - coordinate educational provision for the local perinatal team to support delivery of high-quality core palliative care
 - contribute to the practical, emotional and wellbeing support of perinatal professionals providing palliative care
 - empower professionals and families to raise concerns of babies with potential palliative care needs
 - coordinate routine collection of data for those identified as having palliative care needs to help evaluate service needs.
- Where perinatal palliative care is being provided (by core or specialist teams) consider identifying a named consultant and nurse to support continuity of communication and care planning through the baby's neonatal stay.
- Development of accessible information for families about perinatal palliative care and the various professionals who may be involved in their baby's care.
- Agreed regional arrangements for transport of babies where end-of-life care is anticipated.
- Aim for a named point of contact for palliative and bereavement support for families whose babies require end-of-life care, which may be through a third sector organisation or hospice service.
- 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⁽²⁴⁾.
- Ensure family involvement in the delivery of services by ensuring mechanisms exist for feedback which can inform local service development.
- Support the establishment and maintenance of effective local mechanisms for clinical governance and continuous quality improvement in perinatal palliative care.
- Routine collection and analysis of data around babies with palliative care needs including the support provided and key outcomes.

Perinatal palliative care pathways

Below are some suggested clinical pathways for delivering perinatal palliative care in antenatal and postnatal cases.

Figure 3: Antenatal clinical pathway for delivering palliative care

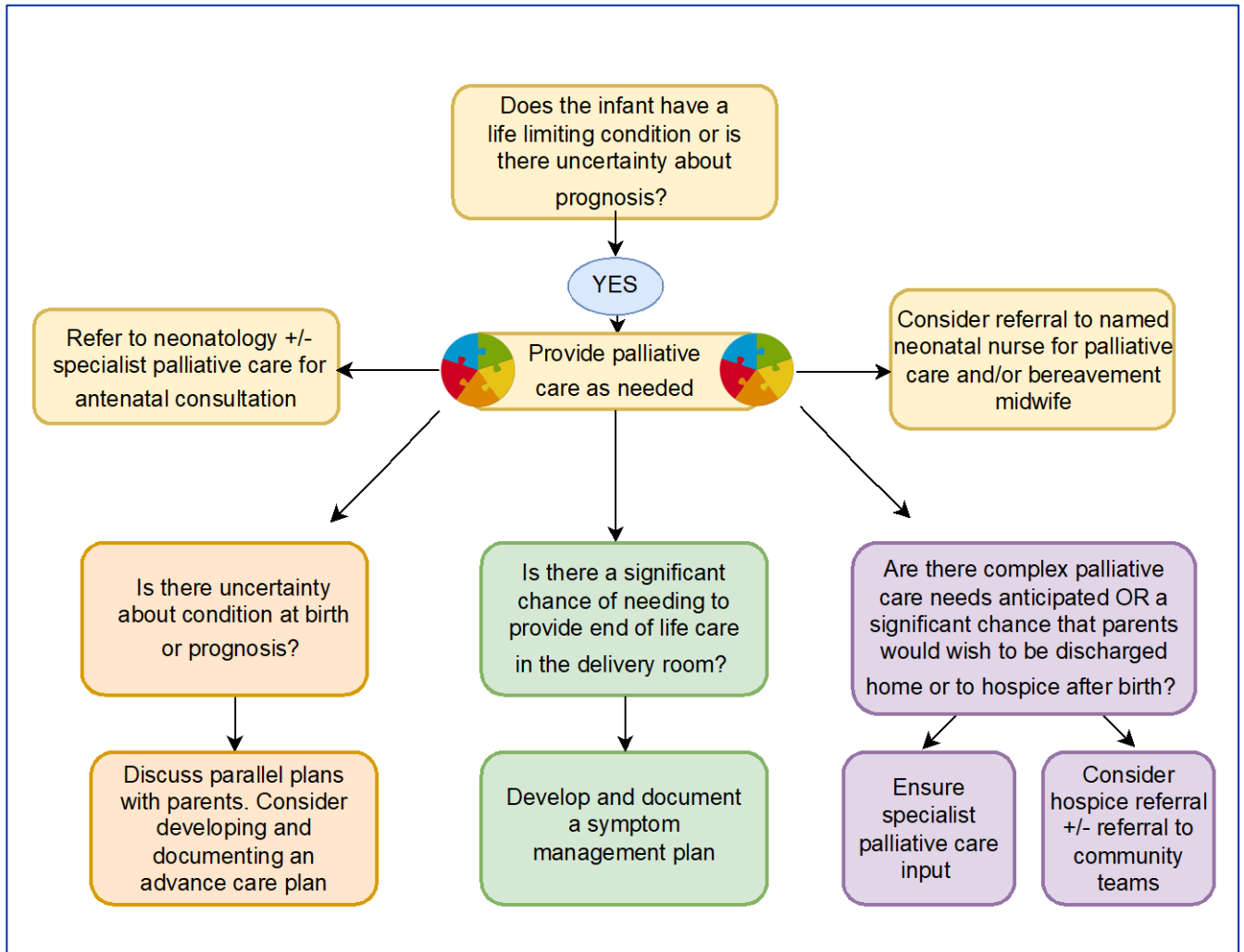
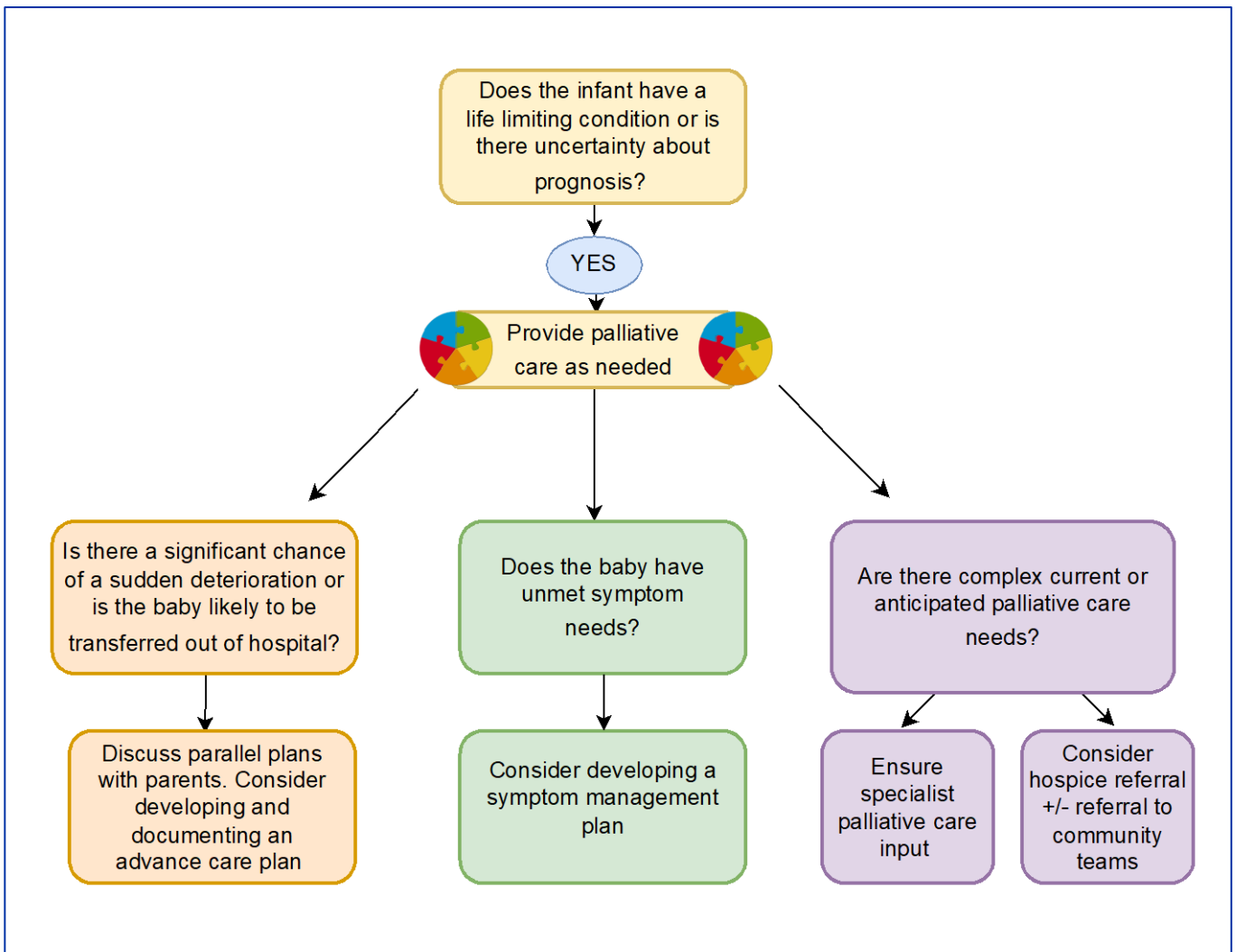


Figure 4: Postnatal clinical pathway for delivering palliative care



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 level 2 to level 3 centres 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 elements of care, is available at these times.

Specialist palliative care teams often have experience in complex discharge planning, and this may be one reason to involve them for advice and support. There can be practical challenges in delivering palliative care in the community due to geographical variation in commissioning of services⁽⁴⁶⁾. 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.

It can be very stressful for families to navigate these changes. Those delivering perinatal palliative care should consider and 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 patient 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. In some cases, it will be appropriate to document in an advance care plan that a baby remains for full escalation of treatment.

(See link to the Child and Young Person's Advance Care Plan collaborative in [Appendix D](#)).

Summary

Uncertainty is difficult. For families, it can be extremely challenging to know how to deal simultaneously with the possibility that their child will survive but also that they may go home empty-handed. 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. This 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 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. But we also have made some specific recommendations.

Recommendations

- Before and after birth, perinatal health professionals should take active steps to identify babies who would benefit from palliative care and to integrate this into routine care.
- Palliative care needs may be identified through diagnoses indicating certain 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 patients 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 Symptom management, Family Support, Parallel planning, Empowerment, 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.
- It is important to collect data around babies with palliative care needs including the support provided and key outcomes.

Research recommendations

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.

- Developing a routine data set on agreed indicators of perinatal palliative care, diagnosis, clinical and service requirements.
- Agree reporting pathways of data set through national reporting records (Badger, MBRRACE, CDR).
- The safety and efficacy of medications for symptom management in the neonatal population.
- Evaluation of the use of screening tools for identifying patients with palliative care needs before and after birth.
- Family experience of perinatal palliative care.

Workforce recommendations

To support the delivery of the perinatal palliative care framework changes in workforce roles and responsibilities will be needed. Bereavement care should also be part of this workforce area. The recommendations are for a neonatal intensive care unit. Further consideration will be needed for local neonatal units and special care as they are delivered as part of children's services.

- Band 8 A perinatal palliative care nursing lead for neonatal intensive care unit to provide leadership, management, training oversight of the antenatal and postnatal palliative care service.
- Specialist nursing team to provide continuity of perinatal palliative care, support education and training. This nursing team can also be part of a team delivering education and training, bereavement care, community care or FI care.
- Emergency and acute delivery of perinatal palliative care part of the routine nursing and medical team roles.
- Nominated neonatal consultant team (2-4 individuals with 2-4 PA) to work with the Band 8 A to provide medical leadership.
- Administrative support for this team to coordinate documentation and communication of advance care plans, MDT, clinical communications, data collection, reporting.

Appendix A: Case examples illustrating principles of perinatal palliative care²

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 fetus may not survive, and given the uncertainty it is agreed the baby would benefit from palliative care.



Sadia and Ali meet initially with a neonatologist with a special interest in palliative care. 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.

Does the baby have palliative care needs?

A further antenatal visit is planned in conjunction with the local specialist palliative care (SPC) team to make plans for delivery. 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.

Consider discussion with specialist palliative care

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 genetic testing (parents decline autopsy). 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 six weeks later and confirms a severe genetic syndrome. Bereavement support is provided by the palliative care team in conjunction with local bereavement midwives.

² These case examples are fictional composite cases.

Perinatal palliative care

Charity 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.

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

Baby Grace 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 Grace 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 delivery is identified as providing continuity support. She considers the elements of perinatal



palliative care and meets with Charity and Eli together with nurse specialising in family support and palliative care. They discuss potential uncertainty and challenges ahead. Grace'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 Grace's older sibling. The consultant agrees with Charity and Eli that it is appropriate for Grace 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 Grace's medical record.

Does the baby have palliative care needs?

At 2 weeks of age, Grace has a life-threatening deterioration with gram negative sepsis and necrotising enterocolitis. She is critically ill, and further conversations with Charity and Eli 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 conversation 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 Grace's heart were to stop they would not wish for cardiac compressions. Support from on call chaplaincy is arranged. Grace has a laparotomy and has resection of most of her small bowel (15cm remaining).

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

Consider discussion with specialist palliative care

Grace 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. Grace 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

Five cardinal questions to ask parents ^(47,48)

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. Where do you get your strength to cope from? What do I need to know about you and your family to help you best?

Introducing palliative care ⁽⁴⁷⁾

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 outlook 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 need extra help from our colleagues in the palliative care team. This team includes doctors and nurses who specialise in the care of children and babies with serious conditions that may or may not improve, and in the support of their families. It is normal for us to refer families to palliative care services for extra help in this type of situation.

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 we 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 ⁽⁴⁹⁾

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):

- Spirituality and faith are important to a number of the families that I meet. Do you have spiritual or religious beliefs that you would like those caring for you and your baby to know about?
- Would you feel able to tell me how these beliefs affect how you cope with difficult times in your life?
- How do your beliefs/faith help you to make decisions?
- To what extent does everyone in the family share the same beliefs?
- Some families appreciate help, for example from hospital chaplains in thinking about their religious beliefs or spiritual questions. Is that something that you would find helpful?
- Are there any rituals or practices which would be helpful or important for you at the moment?
- Is there a faith leader who you would like us to contact on your behalf? (This might be a community faith leader with whom the family has a relationship, or a healthcare chaplain)
- When life is particularly challenging, different people find strength in different places. What about you? I wonder if you feel able to tell me where you find your strength?

Appendix C: Certain and potentially Life-limiting conditions identified in the perinatal period ⁽¹⁶⁾

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 identified.

- High risk or Extremely high risk Extremely preterm delivery e.g., preterm infants at 22-23 weeks gestation⁽⁹⁾.
- Newborn infants with organ failure requiring escalation to extra-corporeal membrane oxygenation or dialysis or solid organ transplantation.
- Newborns where there is a question about providing tracheostomy for long-term ventilation.
- Extremely preterm infants with severe complications e.g., severe necrotising enterocolitis, intraventricular haemorrhage, cystic periventricular leukomalacia, severe chronic lung disease.
- Babies with short gut following bowel resection or long-term dependence on parenteral nutrition.
- Newborn infants with brain injury and high risk of severe disability e.g., infants with severe (Sarnat III) hypoxic-ischaemic encephalopathy.
- Post-natal exome sequencing indicates a causative diagnosis that has the potential to lead to death in early childhood.
- Severe chromosomal abnormality eg Trisomy 13 and 18 (including mosaicism), triploidy
- Severe congenital cardiac conditions that may not be amenable to surgery, or only with severe morbidity e.g., single ventricle conditions.
- Severe fetal cardiomyopathy.
- Severe hydrops fetalis.
- Prolonged preterm rupture of membranes from early gestation with oligohydramnios
- Very severe intra-uterine growth restriction.
- Severe diaphragmatic hernia.
- Neonatal or fetal onset neuromuscular disorder e.g., myotonic dystrophy, congenital myopathyspinal muscular atrophy.
- Multiple severe congenital abnormalities (that may or may not be treatable) in the absence of a clear diagnosis.
- Bilateral Renal agenesis.
- Other severe disorders of renal system eg severe multicystic dysplastic kidneys and oligohydramnios, urethral or bladder agenesis.
- Severe skeletal dysplasia (including osteogenesis imperfecta).
- Arthrogyposis with confirmed severe neuromuscular disorder.
- Severe brain abnormality eg Anencephaly, Craniorachischisis, Hydranencephaly, Holoprosencephaly, Iniencephaly, Lissencephaly.
- Vein of Galen malformation.
- Severe lung or airway abnormality (eg Alveolar capillary dysplasia, laryngeal or tracheal atresia).
- Severe congenital skin disorder eg Epidermolysis bullosa, Harlequin fetus.

Appendix D: Useful resources

- 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
- Together for Short Lives
- Bliss
- Antenatal Results and Choices
- Sands
- Association of Paediatric Palliative Medicine Formulary
- Resources for staff support

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