



# Palliaped

A network of specialists sharing information  
for high-quality palliative care

Issue January 2023

## Perinatal palliative care: focus on needs through gentle guidance

*Alexandra Mancini-Smith RGN, MSc, BSc*

*National Lead Nurse for Neonatal Palliative Care*

*Chelsea & Westminster NHS Foundation Trust, London, UK*

No parent ever expects to be told that their baby may die before they are born, possibly die at the time of delivery or shortly after, and if they do survive, that their future may continue to be uncertain. Healthcare professionals must be available to *accompany parents* during this devastating time, offering *gentle guidance* and *supporting their choices*.

Nothing can take away the intense pain or the devastation they may feel following the loss of the imagined future of their baby; how we support them through this period will be vitally important for how the whole family continues living [1].

Lottie King, mother to Leo, Oska, and Dax says ***‘You have the power to change the trajectory of grief for parents, siblings and the whole family.’***

Perinatal Palliative Care is an opportunity for the multi-professional team to support parents across the continuum of care, including alongside life-sustaining treatment, whilst maximizing the quality of life for the baby and their whole family.

*This document is developed exclusively by Polistudium Srl, owner of the domain [www.palliaped.com](http://www.palliaped.com) (who remains the sole owner of the rights to these documents and responsible for their contents) or Polistudium Srl has acquired the rights of economic use from third parties. This specific document can be used exclusively by users of the Palliaped website who have registered them for professional needs only. Citations and partial reproduction are allowed, within the limits of copyright law, provided they are accompanied by the indication of the source "Palliaped" and the relative web address*



# Palliaped

A network of specialists sharing information  
for high-quality palliative care

Issue January 2023

How can we, as healthcare professionals, assist parents in this situation to explore their wishes and choices for their baby and the wider family?

### Key points to consider in Perinatal Palliative Care:

- Wherever possible, allocate **one key person** who will be the main point of contact for the parents. This will ensure consistency in planning, will reduce the times the parents have to repeat their story and will help with the coordination of several different teams who may be involved in the baby's care, including the inclusion of the community palliative care team and children's hospices [1,2]. This person may be a midwife or neonatal nurse and would ideally meet the parents at the earliest opportunity in the pregnancy. They will have a unique relationship with these parents, knowing their goals, specific needs, values, and wishes for their baby.
- **“What matters most for you and your family”**: By asking parents directly, **‘what is most important for you?’** will enable the healthcare team to support them and address their needs. Every family is unique and will want something specific for their own family. Parents may also wish for different things from each other. For many parents, this is the time when they will learn to be parents, and they may need gentle



# Palliaped

A network of specialists sharing information  
for high-quality palliative care

**Issue January 2023**

guidance from healthcare professionals regarding choices with where they might like to be and whom they would like to have with them.

- **Time, Space, Active Listening, and being present:** Parents tell us that because of the uncertain circumstances, often friends and family don't congratulate them on their pregnancy or birth of their baby, and there are no celebration cards. For this reason, it's important that the baby is acknowledged as a family member. This can be done by asking if they have chosen a name for their baby, asking permission to use it, and offering congratulations. Following initial discussions with parents, offer further opportunities to meet with them and time to help absorb the information shared and explore any further questions they may have. We can try to help them have the most precious moments and experiences together as a family [3]. We can do so by speaking clearly, honestly, and with kindness and compassion. There may be language differences, always offer the use of an interpreter.



# Palliaped

A network of specialists sharing information  
for high-quality palliative care

Issue January 2023

- **Planning care with flexibility:** Fundamental to planning the best possible care is always having a plan that parents have created in partnership with the healthcare team and is regularly reviewed. Parents are central to making care plans for their baby, with healthcare teams empowering their decisions & choices, and the focus must be on nurturing and enhancing family experiences [1].

Particular attention must be given to ensuring parents' cultural, religious, and diverse needs are met, particularly important rituals and traditions. **Creating a birth plan and advance care plan in partnership** can assist in approaching conversations and discussing factors that the parents may not have yet considered. If this is a multiple pregnancy, consideration must be given to all babies and acknowledgment that they may be separated from the mother [4]. Revisit the plan regularly, parents may change their minds, and the baby's clinical condition and needs may change, which requires flexibility. Parallel planning must be incorporated into the care plan, which is making plans for several scenarios, and it's important to reassure that their baby will be reviewed and assessed at the time of birth [2].



# Palliaped

*A network of specialists sharing information  
for high-quality palliative care*

**Issue January 2023**

**Parents must be central to making choices and plans for their baby and family. The focus must be on nurturing and enhancing the parenting experiences with guidance and support from the healthcare team.**

***'We only have the choices you give us'***

Nadia Leake, Mum to Raif, Harrison & Mason

## **References**

1. Mancini A, Price J and Kerr-Elliott T (2020) Neonatal Palliative Care for Nurses. Springer Nature, <https://link.springer.com/book/10.1007/978-3-030-31877-2>
2. Together for Short Lives (TFSL) (2017) A Perinatal Pathway for Babies with Palliative Care Needs. 2<sup>nd</sup> Edition. London <https://www.togetherforshortlives.org.uk/resource/perinatal-pathway-babies-palliative-care-needs/>
3. Clarke P, Allen E, Atuona S and Cawley P (2021) Delivery room cuddles for extremely preterm babies and parents: concept, practice, safety, parental feedback. Acta Paediatrica 2021;110:1439-1449 <https://onlinelibrary.wiley.com/doi/full/10.1111/apa.15716>
4. Neonatal Butterfly Project <https://www.neonatalbutterflyproject.org>



## Appendix 1. Key practical points to consider throughout the Perinatal Period

<b>Antenatal</b>
<ul style="list-style-type: none"><li>• Taking photographs of the unborn baby and the pregnant bump</li><li>• Visiting special places together as a family, creating special memories</li><li>• Observing family traditions/beliefs/culture/religion</li><li>• Using the baby's name</li><li>• Seeking opportunities to celebrate the pregnancy with cards and balloons</li><li>• Developing a Birth Plan alongside an Advance Care Plan</li><li>• If this is a multiple pregnancy, consideration must be given to keeping the babies together</li><li>• Discussing how the parents would like to feed their baby, considering lactation and loss, and offering choices for donating their expressed breast milk*</li><li>• Consider the mother's own health needs</li><li>• Consider the words you use, sensitive and compassionate terminology</li></ul>
<b>Delivery</b>
<ul style="list-style-type: none"><li>• Keeping Mother and baby together wherever possible is a priority</li><li>• Plan for delivery, there may be a plan discussed for a cesarean section, which may increase the chance for parents to meet their baby alive</li><li>• The birthing environment to be considered, low lights, gentle, calm music</li><li>• Warmth, comfort and basic needs of the baby</li><li>• Skin-to-skin-opportunity at the time of birth (<a href="#">WHO recommendations, 2020</a>)</li><li>• Extended time with parents in the delivery room. Experience being a family together; this may be the only opportunity for cuddles as a family before the baby is transferred to the Neonatal Unit (Clarke et al 2021)</li><li>• Who would the parents like to be at the birth - other children, a religious person, or an important cultural person</li><li>• Tangible memories such as taking photographs, footprints, and creating special memories</li></ul>
<b>Post Delivery/Neonatal period</b>
<ul style="list-style-type: none"><li>• Keeping Mother and baby together wherever possible is a priority</li><li>• Consider minimizing separation -The mother might be in another hospital for her own care/other babies if multiple births</li></ul>



# Palliaped

A network of specialists sharing information  
for high-quality palliative care

Issue January 2023

- Assess the baby's clinical condition and needs regularly
- Continuing support for the whole family
- Share ALL plans with other teams involved in the baby's care
- Consider transfer to a local children's hospice if available

\* British Association for Perinatal Medicine (BAPM) (2022) Lactation and Loss: Management of lactation following the death of a baby <https://www.bapm.org/resources/lactation-and-loss-management-of-lactation-following-the-death-of-a-baby>