NEONATOLOGY

Neonatal palliative care

Who benefits, how to recognize them and what the care includes. Hint: it is **not** only end-of-life care.

References

Ellis KL, Carter BS. Perinatal Palliative Care. In: Martin RJ, Fanaroff AA (eds). *Fanaroff and Martin's Neonatal-Perinatal Medicine*, 12th ed. Elsevier; ch. 44, p. 752–763.

Wilkinson D, Bertaud S, Mancini A, Murdoch E; BAPM Working Group. Recognising uncertainty: an integrated framework for palliative care in perinatal medicine. *Arch Dis Child Fetal Neonatal Ed*. 2025;110:F236–F244.

WHAT IT IS

Care that walks alongside treatment

Perinatal palliative care is coordinated, interdisciplinary care to improve quality of life and comfort for babies with life-limiting conditions and for their families, from prenatal diagnosis to bereavement.

✅ It can coexist with full intensive care

Families can receive palliative support while survival-focused treatment continues.

❌ It does not mean "giving up"

It means planning for life while preparing for the possibility of death.

WHO BENEFITS

Three groups to keep in mind

👶

Extremely preterm infants

At the limit of viability, where uncertainty is high and complications such as severe IVH, pulmonary hemorrhage or NEC may follow.

🧬

Life-limiting diagnoses

Before or after birth: chromosomal, genetic, structural or metabolic conditions known to shorten life.

⏳

"Long-suffering" NICU patients

Babies who reach a plateau despite good intensive care, where burdens seem to outweigh benefits.

TRIGGER DIAGNOSES

Examples that should prompt a consult

🧠 CNS

Severe HIE, severe neural tube defects, neuronal migration disorders

❤️ Cardiac

Starting ECMO, single-ventricle physiology (e.g., HLHS)

🧬 Genetic

Trisomy 13 or 18, severe metabolic and mitochondrial disorders

🫁 Respiratory / renal

Severe pulmonary hypoplasia, renal agenesis, Potter sequence

🦴 Musculoskeletal

SMA type 1, thanatophoric dysplasia, severe osteogenesis imperfecta

⚖️ Other

Extreme prematurity, extremely low birth weight, severe twin-twin transfusion

Adapted from Box 44.1 (Ellis & Carter). Not an exhaustive list.

HOW TO RECOGNIZE

Three doors to palliative care

1 · The diagnosis

A condition that is certainly or potentially life-limiting, before or after birth.

2 · Team or family concern

Any member of the team, or the parents, may raise a worry. Disagreement itself often signals an uncertain prognosis.

3 · Screening

Asking the "surprise question" about every baby in the unit.

Based on the BAPM framework (Wilkinson et al., 2025).

SCREENING TOOL

The surprise question

"Would you be surprised if this baby died?"

If the answer is "no"

Open the conversation about a palliative approach and parallel planning.

In neonates

A 2025 NICU study found a consistently high negative predictive value, with the best positive predictive value at day 7 of life. Use it to start conversations, not to predict death.

Asenjo S et al. Eur J Pediatr. 2025;184. doi:10.1007/s00431-024-05879-8

GOALS OF CARE

Not all or nothing: a spectrum

Comfort only — **Full support**

Some families choose comfort measures only. Others want every available intervention. Many choose something in between, such as resuscitation with limits defined in advance.

🔄 Parallel planning

Plan for life and, at the same time, for possible deterioration. Decisions are fluid and should be revisited as the baby's condition changes.

Adapted from Fig. 44.1 (Ellis & Carter).

WHAT THE CARE INCLUDES

Five key elements

🤝 Support

The whole family: siblings, social, financial and spiritual needs.

💪 Empower

Help parents be parents: holding, feeding, bathing, skin-to-skin.

🗺️ Plan

Parallel and advance care plans, reviewed regularly.

💊 Treat

Pain, dyspnea, agitation, seizures and secretions.

🕊️ Loss

Grief and bereavement care, before and after death.

COMFORT FIRST

Symptom management

Start without drugs

Skin-to-skin, swaddling, holding, non-nutritive sucking, breast milk scent, massage and a calm environment.

Opioids are the mainstay

Morphine and fentanyl are the most used in the NICU. Adjuncts such as dexmedetomidine, benzodiazepines or gabapentin may help selected babies.

Adequate pain control does not hasten death

When the intent is to relieve suffering, the principle of double effect supports treatment.

Less is more

Avoid routine labs and procedures that add no comfort.

MEMORY MAKING

Moments that last a lifetime

Parents who engage in legacy building describe it as deeply meaningful. Offer it early, even before birth, without pressure.

- 📸 Photographs
- 💓 Heartbeat recording
- 🖐️ Hand and footprints
- 🧸 Molds
- ✂️ Lock of hair
- 👕 Special outfits and blankets
- 📖 Baby book
- 🛁 First bath

Where it happens matters less

Families often say that **who** was present matters more than **where** the baby died: NICU, delivery room, hospice or home.

Adapted from Box 44.2 (Ellis & Carter).

TAKE-HOME

Key messages

🌱 Palliative care is **everyone's job** in the NICU, supported by specialists when needed.

⏱️ Start **early**: from diagnosis, not only at the end.

🤲 Respect each family's values and choices across the spectrum of care.

❓ Use triggers and the surprise question to **open conversations**, never to stop investing.

💜 Care for the team too: debriefs and support prevent burnout.

NEOFAST

Neonatal care, made fast.

Calculators and clinical tools built for the NICU, based on the literature.

🌐 Website

neofastapp.com

✈️ Telegram

t.me/neofastapp

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