# Strengthening hospice care for babies

***A London wide project coordinated by CHaL***

## Phase 1 – Scoping Exercise: Easy Read Report

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**Why this review was done**

- CHaL wanted to look at how hospices in London care for babies under 1.
- The aim was to find out what is working, what is not, and what could be improved.

**The review was done by:**

- Sending a questionnaire to the 5 children's hospices in London.
- Looking at relevant research and national guidance
- Speaking to a range of stakeholders in London.
- Talking with hospices outside London with well-established models of perinatal care.

**What was not done:**

- A systematic literature review.
- No new patient-level data or prevalence estimates for London.

**Key findings:**

1. **Terminology matters**

- Words matter. Different terms (E.g. perinatal, neonatal, babies; memory-making/treasures/mementoes) can confuse families and referrers.
- Families often prefer words like "babies" help families rather than words like "neonatal" which can feel hospital focused.
- National guidance encourages the use of clear and consistent language.
- Across ChaL there are different job titles used for similar, if not identical roles which also causes confusion amongst stakeholders (E.g. Family support worker / Family practitioner)

2. **Data and Need**

Ultimately, we do not know exactly how many babies in London have palliative care needs and would benefit from hospice services. There is currently no single dataset that captures this information directly. The best we can do is draw on the data that are available, whether national estimates of prevalence, local figures from neonatal units, or mortality statistics and use these to estimate need.

- The prevalence of life-limiting conditions is highest in infants under one year, at 226.5 per 10,000 (Fraser et al, 2021).

- Deaths in babies born before 24 weeks gestation increased in 2024 compared to earlier years (NCMD, 2024)

- National data suggest at least 2% of babies admitted to neonatal units meet palliative care criteria, yet only half of those who died were identified as such (Harnden et al, 2021).

- Babies under the age of 1, account for 61% of all child deaths in England; mortality rates are significantly higher amongst babies from ethnic minority backgrounds and those living in areas of high deprivation.

- London has higher birth rates, greater ethnic diversity, and marked deprivation compared to other regions.

### 3. Current reach

- Referrals only show babies who do reach hospices. Estimating unmet needs is difficult.
- Referral rates and patterns differed across the hospices with no clear trend.

### 4. Referral Pathways

- Most referrals come from neonatal units, foetal medicine, or tertiary palliative care teams.
- All hospices accept antenatal referrals.
- Late referrals are too common.
- BAPM (2024) encourages referrals based on uncertainty, not rigid criteria:

> ***"If you're thinking about a referral, pick up the phone."***

- Barriers to referral include concerns over professional boundaries, or hospices "taking over"; misunderstandings of hospice services, previous referrals or requests being turned down; variation in hospice offers and locality causing confusion; referral forms being too long / complicated.
- Enablers to referral include hospices "in-reaching" to neonatal units and study days / education.

### 4. What hospices offer

- All hospices provide: respite, end-of-life care, bereavement, care after death, support for the whole family.
- Examples of additional services include the Perinatal CNS based at Shooting Star, a specialist midwife role at Noah's Ark, and a pathway for babies born at 22-24 weeks at Demelza.

- Families get different services depending on where they live which risks inequity.

## 5. In-reach to Neonatal Units

- All hospices provide some form of in-reach but who and what is provided differs across CHaL.
- Highly valued by neonatal staff and families; needs to be regular and consistent to build trust.
- Neonatal teams spoke highly of support workers but expressed in-reach offer should also include nursing input.

## 6. Education and training

- Ongoing study days hosted annually by each hospice in partnership with London Neonatal Operational Delivery Network.

- Stakeholders in hospital teams requested more “bite-size” sessions (30–60 min) to raise awareness of hospice services and offered reciprocal training for hospices on basic neonatal care.

## 7. Challenges and barriers to accessing hospice care

- Late referrals compromising hospice offer.
- Location of physical building.
- Confusion about criteria and hospice services.
- Shortage of staff:

> ***“When you keep being told they can’t help with a request or their beds are closed, in the end you just assume it’s going to be a no, and stop referring”***

- Differences between hospices (services, job titles, referral forms).
- Cultural and language barriers for some families.
- Inequity:

> ***“Hospice services shouldn’t be a postcode lottery”.***

## 8. Stakeholder views

- Strong support for hospices but frustration with variation and inconsistency.
- In-reach is praised but must include nurses as well as support workers.
- More cultural sensitivity and translated information needed.
- Call for ***“coordination and collaboration not competition”.***

## 9. Learning from other regions

- **Claire House**: consultant nurse, referral based on uncertainty and automatic referral <25 weeks, broad antenatal offer.
- **Forget Me Not**: perinatal mental health, lactation and donation of milk initiatives, creative bonding activities (free 4D scans), “rainbow” baby groups.

- **Hope House**: weekly in-reach, strong foetal medicine links, early referral as the norm.
- **Keech**: long-standing neonatal pathway, part of monthly hospital meetings, excellent links with foetal medicine.

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**Key Messages**

1. **Refer based on uncertainty and prematurity** -don't wait for a diagnosis.
2. **End the postcode lottery —** one core offer for all babies under 1.
3. **Build capacity & confidence —** can joint working reduce chance of referrers hearing "no".
4. **Prioritise equity and access —** adapt support for culture, language, deprivation.
5. **Collaboration not competition—** Joint working between CHaL + ODN is essential for success.

**Recommendations**

- Create a CHaL-London coordination hub to reduce duplication and promote equity: one referral form, consistent referral criteria, core offer, agreed terminology and job titles. Ensure information is consistent with the London Neonatal ODN.
- Strengthen antenatal pathways with foetal medicine teams.
- Expand in-reach roles (CNS, family support, therapy).
- Share bereavement and family support offers across London.
- Monitor data on referrals, ethnicity, and deprivation to track equity of access.

**Summary**

There is clear evidence that the London hospices are already delivering high-quality, innovative care however access can be inconsistent and inequitable. National data confirm that many babies with palliative care needs are discharged home and families benefit most when hospices are involved early, especially antenatally, and when support is consistent, culturally sensitive, and family centred. To achieve this, London hospices could consider moving towards a Pan-London approach, working closely with the Neonatal ODN to embed consistent referral pathways, reliable in-reach, and joint workforce planning.