

"Roots and Horizons"

Learning From Yesterday, Living Today, Shaping The Future

Resources required to provide Neonatal Palliative Care: Supporting the Neonatal Nursing workforce

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'An Introduction to Neonatal Palliative Care'

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<https://www.elearnicpcn.org/>



NEONATAL
NURSES
ASSOCIATION

Bliss

for babies born
premature or sick

National Neonatal Palliative Care Programme



British Association of
Perinatal Medicine



together
for short
lives





We only have the choices you give us'



Nadia Leake, Mum to Raif, Harrison & Mason

Data-driven approach to understanding neonatal palliative care needs in England and Wales: a population-based study 2015–2020

Fergus Harnden ^{1,2} Julia Lanoue,² Neena Modi ^{1,2} Sabita N Uthaya ^{1,2} Cheryl Battersby ^{1,2} on behalf of the UK Neonatal Collaborative



Effect of national guidance on survival for babies born at 22 weeks' gestation in England and Wales: population based cohort study

Lucy K Smith ¹ Emily van Blankenstein,² Grenville Fox,³ Sarah E Seaton ¹ Mario Martínez-Jiménez,⁴ Stavros Petrou,⁵ Cheryl Battersby,² MBRRACE-UK Perinatal Surveillance Group, UK Neonatal Collaborative

- Approximately 2.1% of NNU admissions ~2,000-2500 babies/year palliative care needs
- Underestimation of population as only includes NNU admissions
- Large proportion are discharged home and to the community

High palliative care needs among families with babies born prematurely

- Risk of death among 22 weeks:
 - 7 in 10 admitted to NNU
- National data help inform resource needs to support families

What are the **resources** required to provide safe, effective, equitable Neonatal Palliative Care?

Appropriately skilled , trained & resilient Neonatal Nursing workforce, with dedicated specialist quality roles with expertise to coordinate care



Parents tell us what they want

- Consistent, honest & timely information
- **Choices**
- Time with their baby and **family experience**
- Listened to
- **Partners** in their baby's care & planning
- Coordination of care
- Gentle guidance



*'It was **invaluable** having a **named point of contact** throughout our neonatal stay. Our baby, Alice was born extremely prematurely at 22 weeks gestation and we didn't know if she would live or die.*

*The **uncertainty** was **excruciating**, but the **dedicated nurse** guided us through each step answering our questions and supporting us.*

*Alice was on the neonatal unit for 5 months , **her future is still uncertain** and she has **complex health needs**.*

*We are now being supported at home by our local children's hospice, which **helps us thrive as a family**'*

Survey of National Neonatal Nurses Network who provide support to parents across England

Survey

- Via email to 184 Neonatal Nurses
- Secure & confidential

Questions asked

- What is the most challenging aspect of your role?
- What would help you be more effective in your role?

Responses

- Received by return email
- 138 (75%) nurses responded

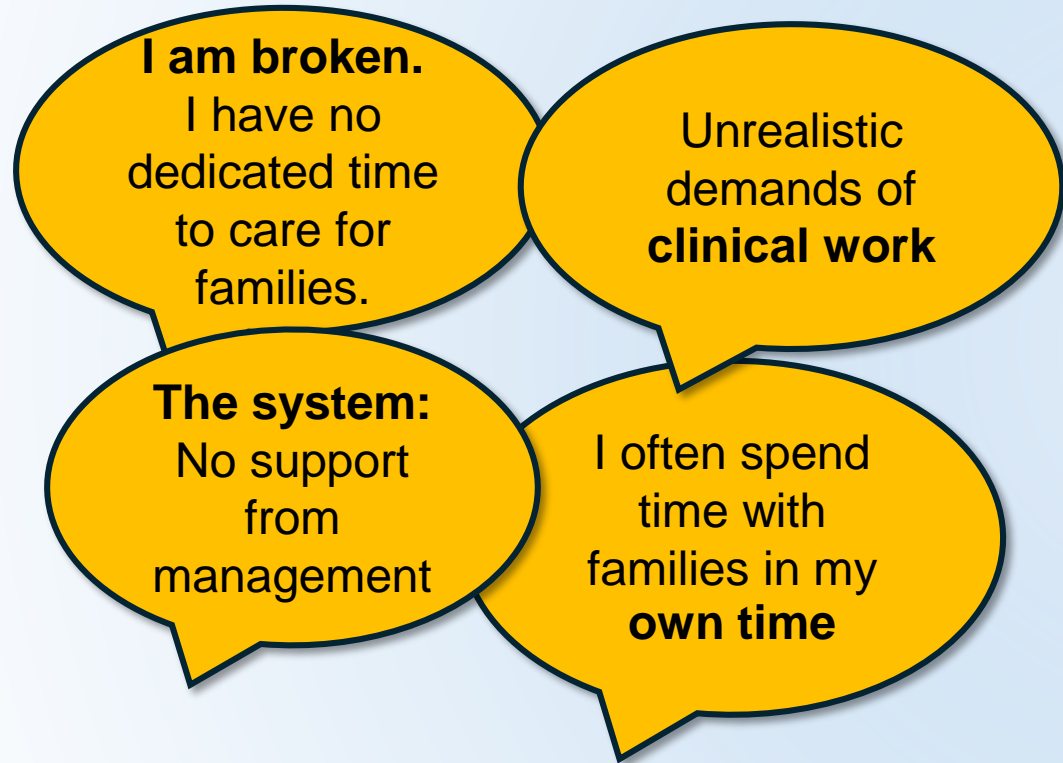
What is the most challenging aspect of your role?

- Limited support from management
- No time-clinical needs
- Little time to spend with families
- Demands of clinical work

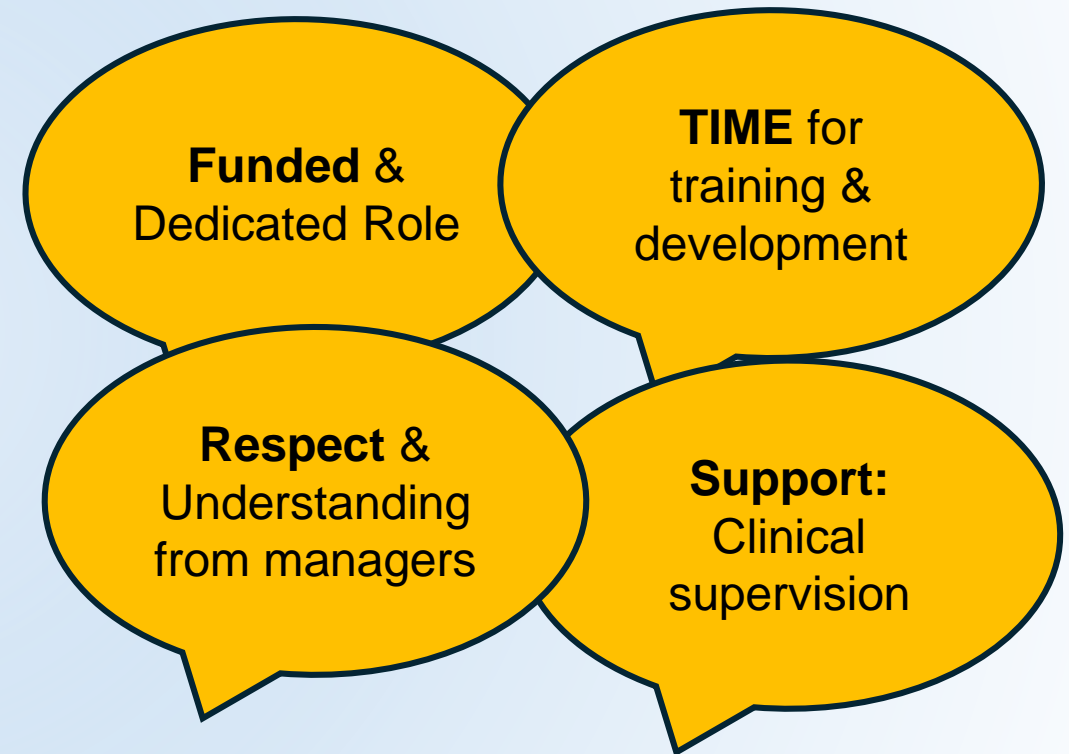
What would help you be more effective in your role?

- Funded & dedicated role
- Time allocated to families
- Understanding from colleagues
- Time for training & development

What is the most challenging aspect of your role?



What would help you be more effective in your role?



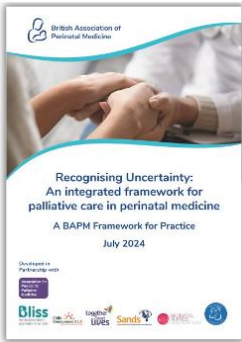
Managing Uncertainty-*What's Important to Families*

Fetal Medicine, Maternity, Neonatal, Community, Children's Services , Children's Hospices
Continuum of Care



Early honest conversations
Parallel Planning
Advanced communication skills
Compassionate Leadership
Personalised Care
Support for the team
Workforce development





Workforce Recommendations

<https://www.bapm.org/resources/palliative-care-in-perinatal-medicine-framework>

Recognising uncertainty: an integrated framework for palliative care in perinatal medicine
A BAPM Framework for Practice

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:
 - Perinatal palliative care regional and local nursing lead for neonatal intensive care units to provide leadership, management, family support and training
 - Lead neonatal consultant role for palliative and bereavement care
 - Local and regional bereavement midwifery role
 - 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 paediatric palliative care consultant.

Lead medical and nursing dedicated time to include:

- Education and training for nursing and medical teams.
- Emotional and practical support for families.
- Weekly meeting (together with on-service consultants, psychology/mental health support and FICare team to support core palliative care).
- Weekly meeting with fetal medicine.
- Regular meeting with specialist palliative care.
- MDTs to support transition and advance care planning.
- Joint meetings with PMRT – review of care provision, education and training for nursing and medical teams.
- Report of service delivery and outcomes.
- Participating in network/national service and professional meetings.

Nursing & Midwifery Specialist Roles

- Dependent on number of care days delivered and number of sites covered

REGIONAL

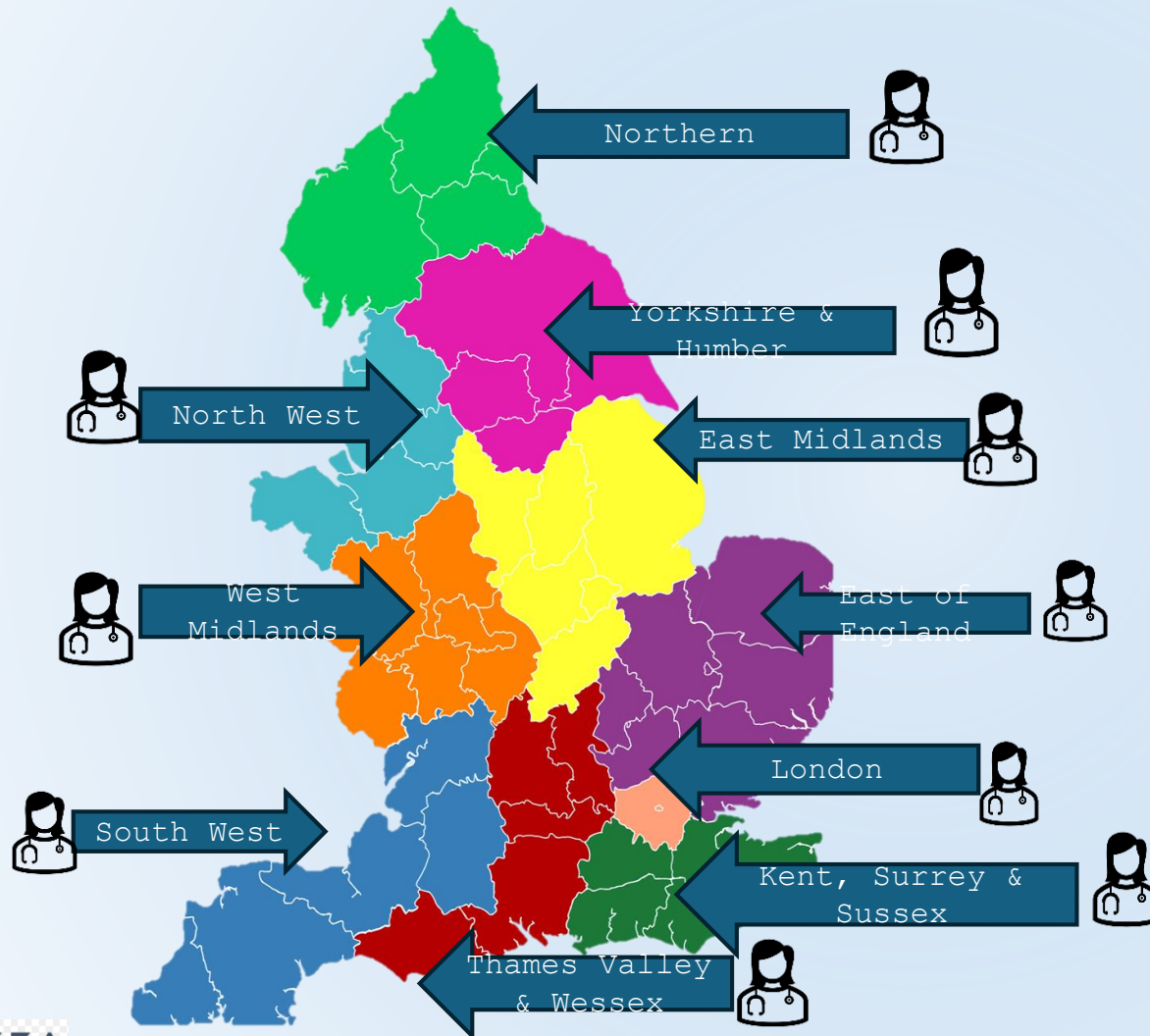
Neonatal Palliative Care Nurse Regional role for each of 10 regions/Network/ODNs

1.0 WTE Band 8 per region/Network/ODN

- Provide professional and strategic leadership across the region on the development and operational delivery of safe effective and equitable perinatal palliative care services through working with local, regional and national teams. This should include working with specialist palliative care teams, hospice and 3rd sector organisations
- Provide leadership on the governance, assurance & surveillance of delivery of national guidance, standards, best practice, workforce development, training needs and delivery, patient and staff feedback, quality safety performance indicators.
- Engage in MDT leadership with other aligned regional and network leads; bereavement, FI care, network, to ensure efficiency of integrated pathways
- Provide oversight of perinatal palliative care team involvement in perinatal mortality review process
- Provide leadership on education and training programmes to support consistent best practice
- Oversee access to restorative clinical supervision is for lead nurses supported by PNA's and designated psychologists
- No direct patient care, but work closely with all lead nurses across the region including on site presence at all of the regional units

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 2024.

Regional- Neonatal Network Nursing Structure



10 Regions/Neonatal Networks in England

led by

10 Regional Neonatal Palliative Care Specialist Nurses

Summary

Neonatal Nurses are our most valuable resource

- Realistic **financial investment** for the healthcare system
- Develop a **resilient** nursing workforce
- **Commissioned** Regional Neonatal Palliative Care Specialist Nurse Roles
- Respect, Value & **Retain expertise & specialist knowledge**
- Access to specialist **training & education**
- National Neonatal Palliative & Bereavement Care Nurses' Network
- **Support for teams**, networking, build resilience & peer support
- **Equitable & consistent for babies & their families**

Safe, Effective, Consistent & High Quality Equitable Care for Babies & their families



Good training, guidance and support is essential to empowering staff and to reassure us as parents, that we do not have to worry about the practical aspects of our babies' condition.

We can then concentrate on being the best parents we can be, for whatever time we have left with our precious children"

Caroline, Brigid's Mum (2014)

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