



CONFERENCE SUPPLEMENT 2025



Speaker: Jo Bennett, Lead for Palliative Care, Transition & Outreach

Talk: Neonatal Palliative Care service model – South West ODN

The South West Neonatal Network established the Lead Nurse for Transition role in 2021 in response to the Neonatal Critical Care Review, recognising the need for dedicated support in palliative and bereavement care, neonatal outreach, transitional care, and the transition to paediatric services. While these critical areas were embedded within the Neonatal Network workplan, additional capacity was required to ensure their effective leadership and implementation.

The Lead Nurse for Transition provides leadership in these areas, working collaboratively with the wider Neonatal Network team, who remain engaged across various aspects of this work. The Neonatal Network remains committed to supporting neonatal services and professionals in delivering compassionate, family-integrated care, with a focus on enhancing confidence in providing personalised, respectful care to infants and families navigating complex health needs and uncertain prognoses. Strengthening regional pathways ensures families receive coordinated, holistic support throughout their neonatal journey and beyond

Key Responsibilities for the Neonatal Network Lead Nurse for Transition.

Supporting Families – listen and understand the needs of families experiencing neonatal care within the SW through regional feedback mechanisms and a collaborative approach to sharing feedback across the pathway.

Communicating Well – advance the offer and opportunity for restorative practice across the workforce through regional personalised care education offers and the regional PNA community of practice.

Enabling Family Choices – Work in collaboration with families to develop regional programmes of work and advocate for partnership working across the SW Neonatal Services.

Knowledge and Understanding - continue to build and strengthen the offer for learners at all levels of experience to develop deeper thinking around palliative care through the on-going regional forums and specialist interest groups.

Collaborative Working – develop links and working relationships with other services in the acute and primary care sectors, as well as national groups supporting national work in developing neonatal palliative care services & resources, along with raising the profile of this area of care.

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Speakers: **Dr Fauzia Paize**, Consultant Neonatologist, **Kat Williams**, Perinatal Consultant Nurse, Claire House & **Caroline Batin-Robinson**, Neonatal Palliative Care Specialist Nurse, NWNODN

Talk: Parallel planning for extremely premature babies: A model of care

Babies born less than 28 weeks, but particularly those born less than 25 weeks gestation face significant medical challenges, often requiring extensive neonatal intensive care. While advances in neonatal medicine have improved survival rates, many extremely preterm infants still experience serious complications, including respiratory distress, intracranial bleeds, infections, and long-term neurodevelopmental impairments. In these complex situations, children's hospice support and parallel planning play a crucial role in ensuring comprehensive, compassionate, and family-centred care. Parallel planning in the under 25 week babies is a structured approach that ensures babies receive appropriate medical interventions while also considering palliative care options if needed. It allows healthcare professionals and families to make realistic, compassionate, and flexible decisions based on the baby's condition. Rather than focusing exclusively on either aggressive treatment or palliative care, parallel planning acknowledges the uncertainties of extreme prematurity and prepares for multiple possible outcomes.

The key components of parallel planning in this group of babies in Liverpool include:

- Open and honest discussions with parents, helping them understand potential outcomes.
- Advanced care planning, including decisions about resuscitation, ventilation, and long-term support with integration of memory making from birth or even during pregnancy if possible
- Palliative care integration, ensuring comfort and dignity if moving towards end of life care.

The Importance of Children's Hospice Support: Children's hospices provide specialised, family-centred palliative care for infants with life-limiting or complex conditions whilst also offering support for parents and the wider family. For babies born less than 25 weeks, hospice support can be crucial in several ways:

- Emotional and Psychological Support - Parents of extremely preterm babies face emotional exhaustion. Hospice teams provide counselling and bereavement support.
- End-of-Life Care in a peaceful setting - If survival is not possible, hospices offer an alternative location for end of life care allowing families to spend precious time together in a more comforting environment and commence their bereavement care
- Pain and Symptom Management - Neonatal complications can cause distressing symptoms. Hospices offer expert pain relief and symptom management plans.
- Respite for Families - If a baby survives with significant disabilities, hospices provide support and short breaks, improving family well-being.

Conclusion

Children's hospice support and parallel planning are essential components of care for babies born less than 25 weeks in Liverpool. They ensure medical, emotional, and ethical considerations are addressed, providing

families with both hope and compassionate care during an incredibly challenging journey, even beyond the neonatal unit



Speaker: Lisa Leppard, Lead Care Coordinator, Wessex

Talk: Promoting care closer to home.

Fetal Medicine to Neonatal Leads Communication:

- When a diagnosis is made A/N (Antenatal), ensure that the local Neonatal Leads are promptly informed by the Fetal Medicine Teams and kept in the loop throughout the process.

Early Communication with NICU Teams:

- Communicate early with local neonatal teams once the baby is admitted to the NICU to ensure smooth transitions and readiness for care.

Link Nurses across ODN (Operational Delivery Networks):

- Establish Link Nurses in each unit within the ODN to ensure families are supported by their local units, fostering relationships and continuous support.

Involvement of Paediatric Palliative Care:

- Engage the Paediatric Palliative Care team early, focusing on Advanced Care Plans (ACPs) and Supportive Management Plans (SMPs). Explore ways in which the team can support both families and local healthcare teams.

Timely Advanced Care Planning (ACP):

- Ensure timely and appropriate development of ACPs, focusing on family wishes and best practices for the baby's condition and future care.

Parallel Planning for Changes in Condition and Treatment:

- Prepare for any changes in the baby's condition or treatment requirements, ensuring plans can adapt quickly.

Open and Honest Communication with Families:

- Foster timely, open, and honest discussions with families, ensuring transparency and understanding of the baby's condition, prognosis, and options for care.





Support from Tertiary Centres to Local Teams:

- Continue support from tertiary care centres to local teams, ensuring consistent guidance. Assign named consultants for ongoing communication and support.

Early Involvement of SOnET Transport Teams:

- Involve the neonatal transport team (SONeT) early to facilitate the transfer of babies requiring palliative care.

Early Multi-Disciplinary Team (MDT) Meetings:

- Hold early MDT meetings with all involved parties to ensure coordinated care and decision-making.

Avoid Last-Minute Referrals:

- Avoid delayed referrals to ensure timely care planning and support, preventing crisis management situations.

Ongoing Support for Families:

- Provide ongoing local support for families. Include maternity care for mothers if needed.

ODN Responsibility for Ongoing Training:

- The ODN should ensure continuous training opportunities for all neonatal staff, focusing on up-to-date care practices and effective communication.

Palliative Care Group Sharing and Continuous Learning:

Establishing an ODN Palliative Care Group allows best practices, and experiences to be shared, and ensure ongoing learning within the network.

This approach ensures comprehensive, compassionate, and coordinated care for families facing complex/palliative care needs for their baby, helping staff at every level remain supported and trained. It's designed to foster communication, teamwork, and the holistic care of both the baby and the family.



Speakers: Trish Rowe & Caroline Duggan, Neonatal Bereavement Nurse, Leeds NICU Y&H ODN

Talk: Parallel planning across multiple specialties

Leeds neonatal palliative care and bereavement services

Leeds Centre for Newborn Care is one of the largest neonatal services in the UK, split over two hospitals in the city: a level three tertiary unit and a level one special care and transitional care service. It provides specialist care to around 1,600 newborn babies each year.

The large multidisciplinary team provides intensive, high dependency and special care to neonatal patients, covering a range of specialisms including; surgery, cardiology, liver, renal, neurology and neurosurgery. Due to the specialist nature of the service, they care for families from the Yorkshire region and beyond.

They are supported by a team of specialist pharmacists, radiologists, audiologists, ophthalmologists, physiotherapists, dieticians, speech therapists, occupational therapists, psychologists and family care nurses to ensure that babies receive the best available care.

The team collaborates with fetal medicine and maternity services to provide antenatal monitoring, support and counselling so they can engage in parallel planning for their baby prior to delivery. This can then be more readily built upon once their baby is born.

The Neonatal Palliative Care and Bereavement Team work within this process. The team consists of two bereavement nurses, with vast neonatal experience who work closely with the Neonatal team to meet the palliative and end of life care needs of babies and their families.

This involves linking with a range of professionals within the Trust and within services from the families' locality. With two thirds of families that experienced neonatal bereavement in the last 12 months being from beyond the Leeds' boundary, their work relies heavily upon strong communication and processes to be effective. They engage with families antenatally, on delivery suite and on the neonatal unit and they continue to support families once they are home. They provide immediate bereavement and practical support, signpost to grief services, ensure families are represented within PMRT and arrange then attend multidisciplinary debriefs. They take a hybrid approach to meet the individualised needs and preferences for each family.

They link with their counterparts within the Trust and Nationally to enable shared learning. This is drawn upon when developing educational packages and resources for the neonatal service. They are available where required to support staff who are providing direct patient care and to follow up for well-being support afterwards.

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Speakers: Sue Thompson, Northern Neonatal Network & Lynne Paterson, Lead Nurse, Northern Neonatal Network

Talk: Northern Neonatal Network developments

Thank you for listening to the work we are doing in the NNN to ensure all our multi-disciplinary teams have knowledge and skills related to neonatal palliative care, and the opportunities we are developing to create a culture for behaviour change.

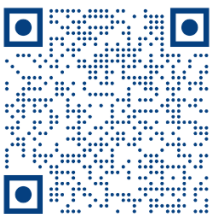
Our work to review and update the Neonatal Comfort Care Bundle was 'on hold' until the publication of Recognising uncertainty: an integrated framework for palliative care in perinatal medicine. We currently have a small working group reviewing the previous content of the bundle, what we need to update/remove/add. This is multidisciplinary with representation from neonatal units, transport service, Children's Holistic Integrated Palliative Care Service (CHIPS), local hospices, third sector organisations, the parental voice and the NNN team.

Our aim is to produce practical, local guidance for palliative care, based on the BAPM Frameworks for practice recognising the local specialist expertise in the NNN. It will support all staff, and reinforce palliative care is 'everyone's business,' from antenatal counselling, delivery room management, palliative care and after death care.

Below is the QR code for Nadia's story of the birth of her preterm twin boys at just 22 weeks, which she has shared on the NNN website.



Below is a QR code to view the video 'Premature birth at 22 weeks of pregnancy'.



Please get in touch if you would like more information about the work we are doing in the NNN: Sue Thompson
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