Neonatal complex & palliative care

Services & Resources to enhance support for families & staff


Alex Mancini

Pan London Lead Nurse for Neonatal Palliative Care
Overview

- Programme of the day
- Handouts-programme, references & resources
- Pre & Post training workshop questionnaire
- Evaluation of the workshop
- Resources on NHS London website
- Awaiting CPD
• What does the term palliative care mean to you?

• Which babies would be considered as having palliative care needs?

• What difference will palliative care make to the baby and their family?

• Are you offering families all the support which is available to them?

• Are families offered choice in partnership with the team?
Learning Outcomes

- Improved understanding of the principles in neonatal palliative care and have an understanding how to identify babies with palliative care needs

- Improved understanding of how to apply those principles and philosophy of care within an acute critical care setting

- Improved understanding of what services and resources are available to families and how to access them

- Improved understanding of collaboration across local services for good practice

- Understand additional resources and services which enhance support for families whose babies have complex and palliative care needs
AIM

To reduce inefficiencies in delivering consistent high quality neonatal palliative care and facilitate smooth care pathways for each baby and their family

To provide practical support for staff working across disciplines and develop robust working relationships across service boundaries

To develop an equitable service across London and empower families to have choice regarding the care of their baby
• Link services together to support families
• Coordinate care and develop robust pathways
• Strategic and advisory role
• Support and upscale professionals
• Individual neonatal units training workshops
• Joint hospice study days
Palliative care education in neonatal units: impact on knowledge and attitudes

Katherine Twamley,1 Paula Kelly,1 Rebecca Moss,1 Alexandra Mancini,1 Finella Craig,1 Michelle Koh,1 Reen Polonsky,1 Myra Bluebond-Langner1

ABSTRACT
Objective To facilitate improved and earlier access to palliative care for babies, a 4-h workshop on the principles, practice and resources in palliative care was delivered in 21 neonatal units across London. This paper assesses the impact of these workshops.

Design As part of mixed methods, procedural evaluation a series of education workshops, a pre and post survey instrument was developed consisting of open and closed questions assessing knowledge of services and attitudes towards palliative care. Before and after each workshop attended were invited to complete the survey.

Setting Neonatal units in hospitals across London, including examples of intensive care, high dependency and special care units.

Results 331 healthcare professionals attended the sessions, and 264 (80%) completed questionnaires. The majority of attendees were experienced neonatal nurses working in neonatal intensive care (61% more than 7 years) but with limited experience of palliative care services. Over 79% of respondents reported that the workshop completely met their learning needs. Pre-session 90% of respondents felt confident referring to palliative care services, compared with 46% before (p=0.001). Analysis of open and closed text responses revealed a shift in attitude after the sessions from a focus on ‘dying of life’, towards integrating palliative care as part of a holistic treatment plan.

Conclusions A short (half day) locally delivered workshop can change attitudes and increase knowledge in neonatal staff. Such a workshop can serve as a first step in facilitating access to and utilisation of a variety of palliative care services.

INTRODUCTION
More children die in the neonatal period than at any other period of childhood.1 Most die in the acute care setting or in neonatal intensive care (NICU).2,3 Improvements in perinatal medicine have led to increased survival for those born at lower gestations, lower birth weight and with complications associated with birth asphyxia and some congenital abnormalities.4-6 Despite these improvements, perinatal health professionals continue to be faced with significant mortality in the neonatal period and a cohort of survivors with complex health needs.5,7 Increasingly, policy and practice guidance advocates palliative care as an integral part of perinatal service provision.7

Palliative care focuses on the prevention of pain and distress of the infant, and on the psychological, social and spiritual support of the family.4,5 The aim is to provide active neonatal care concurrently with palliative and supportive care, ideally from time of diagnosis of a life-limiting or life-threatening condition.4,5,11 Although neonatal staff are experienced in managing seriously ill babies, including attending to symptom management during their final hours of life, research has shown that infants who receive a palliative care consultation undergo fewer medical procedures and receive more supportive services than those without a palliative care consultation.12

The British Association of Perinatal Medicine has outlined the following candidate conditions for which palliative care referral is appropriate: (1) an antenatal or perinatal diagnosis of a condition which is not compatible with long term survival; (2) an antenatal or perinatal diagnosis which carries a high risk of significant morbidity or death; (3) babies born at the margins of viability, where intensive care has been deemed inappropriate; (4) postnatal conditions with a severe impairment of quality of life.
Practical Guidance
Which babies?

- Antenatal diagnosis
- Extreme prematurity
- Birth trauma
- Genetic conditions which are life limiting
- Surgical conditions
- Acute medical conditions
- Continuum of care throughout the time of the baby’s life and beyond
Diagnosis
- Breaking bad news
- MDT discussion

Ongoing Care
- MDT assessment
- Careplan for the whole family

End of Life Care
- Advanced care plan
- Bereavement support
Guidance

- Identify
- Eligibility-diagnosis
- Consider the family’s wishes
- Discuss enhanced support for the whole family
- Consider referral to community palliative care team/hospice
- Consider where the family would like to be
- What is realistic?
1. Care of the infant

1.1 Discussions with parents

1.2 Pain relief and comfort care

- alternative routes for medications-buccal/subcutaneous
- non-nutritive sucking, positioning, calm environment and suckling

1.3 Other symptom control-seizures, secretions

1.4 Physiological monitoring-invasive, blood gas

1.5 Fluids & Nutrition-vomiting, reduce total enteral fluid (pg 12)

1.6 Ventilation & Oxygen-practical, discuss possibility that infant may live

1.7 Location of care-joint care-postnatal ward, home, hospice (Pg.14)
Enhance Neonatal Care

- Enhance neonatal care and support for staff
- Emotional & practical support for siblings
- Community staff support
- Access to established community services
- Develop continuing relationships for the families with community teams
- Continuing family bereavement support
Key components

- Decisions based on the best possible information
- Joint decision making with parents,
- Open and honest communication throughout
- Clear documentation
- Individualised integrated care plan with MDT
- Continuing care of the mother
- Flexible care plan with regular reviews
- Parallel planning
- Advanced care planning
- Haven House - Woodford Green
- Richard House - Beckton
- Demelza - Kent

https://www.google.com/maps/d/viewer?mid=zvO6tbj1tNpl.k6W-xh0w52nM
NDAU Website
### Bliss Charter Audit Tool

#### Standard 2.5 Palliative and end of life care

<table>
<thead>
<tr>
<th>Ref</th>
<th>Summary of criteria</th>
<th>ref</th>
<th>G</th>
<th>A</th>
<th>R</th>
<th>Outline of current practice and / or requirements for ACTION PLAN</th>
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<tbody>
<tr>
<td>2.5A</td>
<td>Units have clear criteria for assessing which babies require palliative care, taking into account diagnosis and prognosis.</td>
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<td>2.5B</td>
<td>Palliative care decisions are made following discussion between parents and senior/suitably trained clinician(s).</td>
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<td>2.5C</td>
<td>Palliative care should be coordinated by a named lead professional and involve a multidisciplinary team.</td>
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<td>2.5D</td>
<td>The baby’s documented care plan is agreed with parents and based on a multidisciplinary assessment, ongoing discussion with parents (incl. personal, faith or spiritual wishes and place of death).</td>
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<td>2.5E</td>
<td>Units have links with children's hospices to support parents and their choices on the baby’s place of death.</td>
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<td>2.5F</td>
<td>Staff are experienced in supportive end of life care and have received appropriate training.</td>
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</table>

#### Action Plan

- **2.5G**: A lead clinician takes through the Bliss booklet: Making Critical Care Decisions with parents and notes the conversation in the baby’s record.
- **2.5H**: Bereavement support coordinated by a named professional is made available if needed.
- **2.5I**: Staff support the rapid discharge of a dying baby to home if the parents wish it. They are competent in involving a GP in this process and can provide a discreet level of support to the family during this time period.
Donation of breast milk

When a baby dies:
Advice for breastfeeding mothers
Practical advice to help you make decisions about how to stop your milk production and what to do with any breast milk you may have stored.

Bliss

NHS
London Neonatal Operational Delivery Network
Neonatal Organ Donation

The diagnosis of death by neurological criteria in infants less than two months old

April 2015

Updated recommendations

Implications for practice

LONDON ORGAN DONATION SERVICES TEAM (NHSBT)

24 HR ON-CALL PAGER
07659 100103

When using the pager please ALWAYS state

- Your name
- The name of the hospital
- Telephone number with STD code
- Any bleep or extension number

The on-call Specialist Nurse will advise on individual referrals

In the event of a pager failure please contact the Duty Office and ask them to contact the on call Specialist Nurse – Organ Donation for London on:

0117 975 7580

For general information or requests for teaching sessions on organ donation please ring the Office on:

0207 166 6922

RCPCH
Royal College of Paediatrics and Child Health
Leading the way in Children’s Health

NHS
London Neonatal Operational Delivery Network
AN UPLIFTING STORY OF BRAVERY

TEDDY: DIED
AFTER JUST
100 MINUTES

NOAH: TWIN
SURVIVED &
IS HEALTHY

Teddy...youngest
organ
donor ever

Brit parents’ incredible battle to donate baby’s kidneys after just 100 mins of life.
Coffee
Neonatal Palliative Care Pathway

For babies and their families with an antenatal diagnosis, on the Neonatal Intensive Care Unit, or being discharged home or to a hospice.

NICU Care Pathway

AM / JH 2011
# CONTACT NUMBERS

**Children’s Community Nursing Team**
for Kensington & Chelsea
0207 349 3258

**Kaleidoscope-Paediatric Palliative Care Team**
K&c, H&F and Westminster
0207 349 3253

**Paediatric Palliative Care Team (London)**
Great Ormond Street Hospital
0207 829 8678

**Shooting Star Chase Children’s Hospice**
(includes all North West London Perinatal Network)
www.shootingstar.org.uk
0208 783 2000

**ACT – The Association for Children’s Palliative Care**
0845 108 2201
www.act.org.uk/

**Children’s Hospice UK**
www.childrenshospice.org.uk/
0117 989 7820

**Rainbow Trust**
Surrey: 01372 363438
Durham: 0191 3864400
Manchester: 0161 3364767
www.rainbowtrust.org.uk/

**SANDS – Stillbirth and neonatal death charity**
www.uk-sands.org/
020 74365881

**Child Bereavement Charity**
www.childbereavement.org.uk/foryoungpeople
01494 446648

**ARC – Antenatal results & choices**
http://www.arc-uk.org/
020 76310285

**BLISS**
www.bliss.org.uk/
020 7378 1122

**RCPCH – Royal College of Paediatrics and Child Health**
020 70926000
www.rcpch.ac.uk/

**BAPM – British Association of Perinatal Medicine**
www.bapm.org.uk/
020 70926085

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### Planning Meeting for the family

**Venue:**

**Agreed planned date of discharge:**

(If known)

- All professionals utilizing the care pathway must sign below

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<th>Name &amp; Details</th>
<th>Date of Involvement</th>
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<td>Neonatal Midwife</td>
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<td>Paed Care nursing team</td>
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<td>Gastro Support</td>
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**NICU Care Pathway**
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AMI 11/11/2011
Rainbow Trust
Remember My Baby

• Tel: 07837 739855
• info@remembermybaby.org.uk

About Us

‘Remember My Baby’ (RMB) is a new UK based registered charity which offers a gift of baby remembrance photography to all UK parents experiencing the loss of their baby before, during or shortly after birth.

Mission.

Our goal is to offer a service of baby remembrance photography to all parents suffering the loss of their baby in every hospital and birth centre across the UK.

Description.

Remember My Baby is a UK registered charity whose professional volunteer photographers visit families who may be experiencing the loss of their baby before, during or shortly after birth.

When a family loses a lifetime’s potential for capturing milestones as their child grows, we will capture a precious baby with parents, siblings and extended family for free. Each family will receive a ‘free gift’ of high resolution digital images with a copyright licence to print for their own personal, non commercial use.
Children's Understanding of Death at Different Ages

Children under 2 years old

- Long before they are able to talk, babies are likely to need to sleep and changes in their environment brought about by the disappearance of a significant person who responded to their needs on a daily basis.
- Toddlers might show a basic understanding of death when they see a dead bird or insect in their garden but they do not usually understand the implications of this, such as the dead bird can't anything or won't ever get up again.

Children from 2 to 6 years old

- Tend to think very literally, therefore it is important to avoid offering explanations of death as 'gone away' or 'lost' which can cause misunderstandings and confusion.
- Often struggle with abstract concepts like forever and find it difficult to grasp that death is permanent. Their limited understanding may lead to an apparent lack of reaction when told of death.

Children of primary school age

- Begin to develop an understanding that death is permanent and final. They may be fascinated by the physical aspects of death or the rituals surrounding it.
- May see death as a person who 'ought to get up' or 'wake up' if you are unkind.
- Begin to develop their imagination and 'magical thinking', which reinforces the belief that thoughts or actions caused the death and can lead them to fill the gap in their knowledge.
- May have an awareness of death having a cause and being irreversible, but at a younger age, they might need reminders.
- As they get older, begin to have a more mature understanding of death, realising that it is permanent, universal and an unavoidable part of life.
- Can become fearful as a result of their deepening realisation of the possibility of their own death.

© Written by Roz Holmes for Child Bereavement UK Reviewed July 2011

When your baby dies – a particular sort of grief

When a baby dies, the parents we support speak of a grief that has no comparison, a particular sort of grief. ‘The word ‘death’ creates too much in the way of grief and horror for a small child to feel any other way’, states.[Italics] This information has been written with contributions from some of those families including Sarah and Matt who share their story. Sarah was 23 when her first child, a baby girl, was stillborn. She has given permission to share her story to help other parents who might feel there is ‘nothing you can do’.

When a baby dies, it is a very short time, or days before birth due to an antenatal, obstetric, or difficult decision to not and a pregnancy. It is sometimes important to allow a shortened and less intense grief. Nothing could be further from the truth. The intensity of love parents feel for their baby is not less measurable in weeks and months of pregnancy, or the afterbirth hurt is less hurt that might have been, but in the emotional investment they have made in this child. A parent begins their relationship with their baby long before birth and will grieve not only for the baby, but for their hopes and dreams and what their child would have loved had the family.

‘I was beginning to love my baby hot broth, put a nappy on. Aye, up the nose, take him to the specialist and show him off for the first time. ’Complete, mother of Thomas who lived for one day.

Grieving for your baby

There is no right way to grieve the loss of a baby. Everyone will do it their own way and in their own time, even within the same family. Grief means feeling and expressing all the emotions you have, whatever they might be. For some parents, grief is so intense they can think what they are feeling must be wrong. We feel as though we are going out of my mind because I had never experienced such intense feelings before.’[Italics] The feelings of grief are so intense that the parents begin to feel numbness. It is natural to feel this way. Your body's natural way of coping with grief is to numbness. It is natural to feel this way. The parents have the support to talk about everything with their baby.

When a baby dies, there is often the normal reminders of what has been lost. A mother's body will still respond as though her baby is alive. She will still experience the physical and emotional prenatal feelings but without the joy of a baby to hold and care for. This is particularly distressing and can be very hard to bear.

Do your best to give yourself a time and place to grieve, to sit alone and focus on your baby. You may find yourself trying to avoid it – throwing yourself into work or other activities, or just keeping busy. People close to you may even encourage you to forget, but thinking about the baby who has died, and the way we feel, is an important part of the grieving process.

Some parents repeatedly comment on the importance of a baby’sowl. For some parents this can be a relief. They take the view that if there is nothing wrong, there can be no harm to another pregnancy for others having no answer to the question why?’[Italics] creates immense distress. ‘We all cannot accept why this happened to our family – there are no reasons’, said the mother of Joe who died suddenly at 6 weeks old.

Some parents blame themselves, they feel they have failed their baby and hated as parents. Women may consider they have let down their husbands and extended family because they both just can’t bear the thought of it. Even when there are no physical reasons for the baby’s death, it may be difficult to explain. These feelings may provide an explanation that fits with logic but not always one that helps on an emotional level. Often there is a conflict between our head and our heart.

There are times when our heart can not even begin to comprehend what the head knows and makes sense of.
• Post Mortem Consent Forms
• Support for families & staff
• Reports & recommendations
Together for Short Lives

- Support
- Resources
Bliss

- Family care nurses
- Bliss volunteers
- Buddy
- Support for families & staff
- Resources
TAMBA

- Helping Hands
- Befriender
Contact A Family

- Information
- Support
- Resources
Antenatal Results and Choices (ARC)

Helping parents and professionals through antenatal screening

ARC is the only national charity helping parents and healthcare professionals through antenatal screening and its consequences.

Around 800,000 women in the UK become pregnant each year. More than 40,000 will be told there is a risk their baby has a serious fetal anomaly. Naturally, this causes a great deal of anxiety and uncertainty. Most parents will ultimately be reassured the pregnancy is progressing as expected. Sadly, some will receive the devastating news that their baby has a serious, sometimes lethal condition or might be told that the outlook is very uncertain.

ARC offers non-directive information and support to parents before, during and after antenatal screening, when they are told their baby has an anomaly, when they are making difficult decisions about continuing with or ending a pregnancy, and when they are coping with complex and painful issues after making a decision, including bereavement.

Need support?
The Lullaby Trust

Safer sleep
Get expert advice on safer baby sleep
Freephone 0808 802 6869

SUPPORT
- Support for families
- Safe sleep for babies
- Support services
- Resources
- Care of next infant

SAFER SLEEP
- Back to sleep
- Bed sharing
- Room temperature

RAISE MONEY
- Brighten a marathon
- Milks in memory
- Organise your own event

TWEET
The Lullaby Trust
Congratulations & well done to our very own Erin who did a skydive on Saturday & raised a massive £150!
Tweet to @LullabyTrust

SOCIAL MEDIA
The Family Fund

- Registered user
- Urgent application
- Short term
- Means tested
- Staged payments
Sibs

The difference Sibs makes

I, an adult sibling, needed help with her relationship with her disabled sister. She was finding it very difficult to...

>> See all case studies

About Sibs

Sibs is the only UK charity representing the needs of siblings of disabled people. Siblings have a lifelong need for information, they often experience social and emotional isolation, and have to cope with difficult situations. They also want to have positive relationships with their disabled brothers and sisters and to be able to choose the role they play in future care. There are over half a million young siblings and 1.7 million adult siblings in the UK.

Who we support

We support siblings of all ages who are growing up with or who have grown up with a brother or sister with any disability, long term chronic illness, or life-limiting condition.

We work with adult siblings

We have a phone and email service for adult siblings for help with any adult sibling issue. We also run workshops for siblings on understanding their brother or sister’s disability and on coping strategies for dealing with difficult sibling issues. These workshops can be bought in by statutory and voluntary agencies. See Workshops for siblings and parents.

We work with young siblings

We provide email information and support to young siblings (children and young people) on any sibling issue. We also run workshops for siblings on understanding their brother or sister’s disability and on coping strategies for dealing with difficult sibling issues. These workshops can be bought in by statutory and voluntary agencies. See Workshops for siblings and parents.

We work with parents of siblings

We have a parenting siblings phone service for parents to help them support siblings with sibling issues such as giving attention, explaining disability, and dealing with sibling feelings. We also run workshops for parents on supporting siblings. These workshops can be bought in by statutory and voluntary agencies. See Workshops for siblings and parents.

We work with service providers

We provide training and consultancy for professionals on supporting siblings, how to develop local services for siblings, and how to run sibling groups using the Sibs PRiME model of groupwork. We run awareness raising events for professionals to help them understand the support needs of siblings. Our training can be bought in by statutory and voluntary agencies. See Training for service providers.

Our vision

Sibs’ long term vision is that every local authority in the UK will have a dedicated sibling service for young siblings and a support network for adult siblings. We will achieve this through:

- Being the UK resource for information, training and research on sibling issues
- Influencing the policies of government and other service providers
- Increasing public awareness of siblings

Connect with Sibs

By phone: 01535 645453
By email: info@sibs.org.uk

Connect with adult siblings

Sibs forum for adult siblings
Collaborative Working

• ‘In Reach’
• ‘Out Reach’
• 2 way process
• Knowledge of what services are available
• Sharing good practice
• Maintain relationships
• Named professional
Additional resource

- September 18th
  Shooting Star House
- October 7th
  Haven House
- December 2015
  Richard House
- January 2016
  Demelza
Scenario workshop
Lunch
• Post questionnaire
• Workshop evaluation
• Maintain relationships
• Alexandra.mancini@chelwest.nhs.uk
## Training dates

<table>
<thead>
<tr>
<th>Date</th>
<th>Neonatal Unit</th>
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<tbody>
<tr>
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<td>Whittington (NC)</td>
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<td>August 14th</td>
<td>North Middx (NE)</td>
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<td>September 8th</td>
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