Impact of Guidelines on the Quality of Care: The UK experience
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What is quality of care?

How do you measure it?
National Guideline Alliance

Version 1.0

End of life care for infants, children and young people: planning and management

Full Guideline

NICE Guideline
Methods, evidence and recommendations
1st July 2016

Archives of Disease in Childhood

Making decisions to limit treatment in life-limiting and life-threatening conditions in children: a framework for practice

Practical guidance for the management of palliative care on neonatal units

1st Edition
January 2016

A Mercier, S Hillery, C Browne, D Wood and M Hadi
How do you measure the impact?

- Parental feedback
- Staff observation-change in neonatal unit culture
- Observed change in behaviour
- Reported increase in collaboration with appropriate/relevant professionals
- Increase in referrals to palliative care services
### Everybody’s business

#### Palliative Care
- NOT end of life care
- Focus on the life of the baby and living for the whole family
- Dual Planning
- Pooling expertise
- Planning for end of life and continuing care after death
- Continuum of care

#### End of Life Care
- Part of palliative care
- Specific time span
- Practical aspects
- Emotional considerations
- Cultural considerations
- Spiritual considerations
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?
### 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>GA</th>
<th>R</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>
<td></td>
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<tr>
<td>2.5B</td>
<td>End of life/palliative care decisions are made following discussion between parents and senior/suitably trained clinicians</td>
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<tr>
<td>2.5C</td>
<td>Palliative care should be coordinated by a named lead professional and involve a multiagency, multidisciplinary team</td>
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<tr>
<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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<tr>
<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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<tr>
<td>2.5F</td>
<td>Staff are experienced in supportive end of life care and have received appropriate training</td>
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#### Outline of current practice and/or requirements for ACTION PLAN

<table>
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<tr>
<td>2.5G</td>
<td>A lead clinician talks through the Bliss booklet Making Critical Care Decisions with parents and notes the conversation in the baby’s record</td>
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<tr>
<td>2.5H</td>
<td>Bereavement support coordinated by a named professional is made available if needed</td>
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<tr>
<td>2.5I</td>
<td>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</td>
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</tbody>
</table>
1. Units have clear criteria for assessing which babies require palliative care, taking into account diagnosis and prognosis.

2. End of life/palliative care decisions are made following discussion between parents and senior/suitably trained clinicians.

3. Palliative care should be coordinated by a named lead professional, but involve a multi-agency, multidisciplinary team.

4. The documented care plan is based on a multidisciplinary assessment and ongoing discussion with parents, including personal, faith or spiritual wishes, and preferred place of death.

5. Units have links with children’s hospices to support parents and their choices on their baby’s place of death.

6. Staff are experienced in supportive end of life care and receive appropriate training.

7. A lead clinician talks through the Bliss booklet Making Critical Care Decisions with parents and notes the conversation in the baby’s record.

8. Bereavement support is coordinated by a named professional, and made available if needed.

9. Staff support the rapid discharge of a dying baby to home if the parents wish it. Neonatal staff will involve the GP in this process and will provide a discreet level of support to the family over this period of time.
Challenges

- Fragmented
- Babies & families are unique
- Conflict within families-cultural/beliefs
- Communication-when do you start conversation?
- Conflict within team
- Conflict between the family & the team
- Infrequent-same people caring for babies
- Lack confidence
- Competing demands
- Expertise concentrated in small group
- Resources?
- Practicalities
- Legalities
- Processes within institutions
- Hospital or Home
- Community support
- Time
Challenges for families

- The family routine is fragmented
- Visiting hours
- Visiting separately
- Other children
- Travel
- Financial loss
- Exhaustion
- Loss & Grief
- Uncertainty
Impact on Quality of Care

- Twins  28 weeks
- TOF
- 6 months
- Twin home at 5 months
- Family fragmented
- Visiting restrictions on NICU
- Many surgeries
- Final surgery
- Sustained severe brain injury
- ? Days, perhaps weeks
- Home
- Support-hospice/NICU
- Died after one week
- Continued family support
Working together

Baby’s needs
Family’s needs
Resources
What is important for that family
What is possible for that family
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
Palliative care education in neonatal units: impact on knowledge and attitudes

Katherine Twamley,1 Paula Kelly,1 Rebecca Moss,1 Alexandra Mancini,2 Finella Craig,3 Michelle Koh,3 Reen Polonsky,2 Myra Bluebond-Langner1

ABSTRACT

Objectives: 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, a processual evaluation of a series of education workshops was conducted, consisting of open and closed questions assessing knowledge of services and attitudes towards palliative care. Before and after each workshop attendees 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 3 years) but with limited experience in palliative care services. Over 75% of respondents reported that the workshop completely met their learning needs. Post-session 90% of respondents felt confident referring to palliative care services, compared with 46% before (p=0.005). Analysis of open and closed text responses revealed a shift in attitude after the sessions from a focus on dying/death 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, low 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.4,7 Increasingly, policy and practice guidance advocates palliative care as an integral part of perinatal service provision.8

Perinatal palliative care focuses on the prevention of pain and distress of the infant, and on the psychological, social and spiritual support of the family.9,10 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.11-13 Although neonatal staff are experienced in managing seriously ill babies, including attending to symptom management during their final hours of life, research has highlighted that infants who receive a palliative care consultation undergo fewer medical procedures and receive more supportive services than those without a palliative care consultation.14,15

The British Association of Perinatal Medicine has outlined the following candidate conditions for which palliative care referral is appropriate: (1) an antenatal or postnatal diagnosis of a condition which is not compatible with long-term survival; (2) an antenatal or postnatal 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) neonatal conditions with a severe impairment of quality of life.

• 2010/2011
• 4 hour workshop
• 21 Neonatal Units
• 331 healthcare professionals
• Attitudes changed
• Increase knowledge
• Facilitate access to & utilise a variety of palliative care services
• Time constraints/funding
• Evaluate the impact
12 month time period
28 NICUs
8 Hospice
540 HCP
Children’s Hospices

- “Menu of options”
- Inhouse or outreach
- Part of palliative care team
Choose a date

Provide a room

Refreshments & lunch

Inter-professional learning-
neonatal, paediatrics, maternity, community

Staff within the network (20-30)

Share good practice & evaluate

Identify lead

CPD

Revalidation
Parents for parents

Review
Outcomes

- All neonatal staff (MDT) are aware of services provided in the community for babies, families including siblings.
- Ongoing training and education in each neonatal unit across the disciplines.
- Research strategies developed in improving and optimising care and experience for babies and families.
- Robust working relationships across service boundaries.
- Development of a specialist nurse to lead each neonatal network.
Evaluation

- Support from the management team, particularly Matrons as well as a lot of interest in attending training days from expanding team of nurses.

- The single most common point of feedback received, was a request for more training opportunities more often.

- Recognition the population of patients is becoming more complex and the team can see the need and benefit of this type of input for families.

- All 3 consultants who attended the first day have recommended it to their colleagues.

- They found the networking opportunities and finding out more about the services available helpful.

- 3 sessions Oct, Feb, Sept - part of a whole day training.
- 75 staff.
Evaluation

- Pre and post training survey
- Referral to palliative care services
- Observations of staff
- Increase choice for families
- Reported increased confidence of staff in accessing services
- Willingness & support for further training
Impact of guidelines on quality of care

- Gather current and relevant information
- Include parents in everything
- Collaboration of interdisciplinary team
- Share that information effectively
- Bring to healthcare professionals
- Professional bodies stipulate you must incorporate the most recent information into your practice
- Own responsibility to seek information and enhance knowledge
- Continue learning
London Neonatal Operational Delivery Network

The London Neonatal Operational Delivery Network, bringing together 28 units across London and their staff to provide well-rounded coordinated care for your baby.
The following presentation is taken from the LCPC Symposium 2016: *When Caring Never Stops – Meeting the Needs of Vulnerable Babies*