The Northern Neonatal Network
An Operational Delivery Network
Website - www.nornet.org.uk

Chair: Deborah Jenkins
Clinical Lead: Dr Sundeep Harigopal
Nurse Lead: Lynne Paterson
Manager: Martyn Boyd
Northern Neonatal Network, Trust Headquarters (Room 248), Sunderland Royal Hospital, Kayll Road, Sunderland, SR4 7TP

deborah.jenkins@stees.nhs.uk
sundeep.harigopal@nuth.nhs.uk
lynne.paterson@stees.nhs.uk
martyn.boyd@chsft.nhs.uk

Guideline for Family Centred Care

March 2014

Due for review - March 2016
Guideline for Family Centred Care

Introduction

This guideline reflects a multidisciplinary approach and draws on the current available evidence in the field of family centred care (FCC). It identifies possible stressors to the family when there is a planned or emergency admission to the neonatal unit.

The target patient group includes any family who is currently or is expected to be cared for in the neonatal unit.

The target professional group is any healthcare professional and support staff caring for families on the unit.

The aim of the guideline is to guide practice within the neonatal unit from the time of admission (or antenatal) to the time of discharge.

Summary of FCC guideline
1. Purpose

The purpose of this guideline is to ensure practice is standardised throughout the Northern Neonatal Network. This provides guidance for all members of the multidisciplinary team.

2. Scope

The target audience of this guideline is any health care professional and support staff caring for the baby and family within the neonatal unit. This guideline applies to all staff working in neonatal units within the Northern Neonatal Network.

3. Definitions

Family centred care: Family centred care is based on the understanding that the family is the baby’s primary source of strength and support and that the family’s perspectives and informed choices are important in clinical decision making. It has been recognised that family centred approaches to neonatal care can enhance parents’ confidence in their role and parental involvement improves emotional, cognitive and physiological outcomes for babies.

Family centred care coordinator: A health care professional who has overall responsibility for ensuring that family centred care is embedded into policy and practice across the neonatal network. The FCC coordinator is responsible for audit, research and instigating evidence based initiatives, this person delivers staff training, acts as a role model and liaises with relevant professionals at network and national level.

Family centred care link: A nominated practitioner, usually a nurse, within an individual hospital, who takes the lead for the provision of family centred care on their unit. They will liaise with and be supported by the FCC coordinator in order to promote FCC.

Parents: The parents are the primary care-givers for the baby/babies. Parents may be the biological mother and father, the legal adoptive parents, same sex couples, single mothers or fathers and any other person who has legal parental responsibility for the child.

Family: Any person whom the parents consider to be part of their family unit, including but not limited to, siblings (biological, step, adopted or foster), grandparents, aunts, uncles, cousins and godparents. Consideration should also be made for families who have little family support but who value the support of a very close friend.

Developmental care: Developmental Care in the NICU can be defined as supportive interventions which assist the baby to develop as normally as possible in a noxious and over-stimulating environment. Unit design, equipment selection, policies, care protocols and staff training help to maintain the basic physical, sensory, and interpersonal needs of the preterm baby while minimizing exposure to noxious and painful stimuli.
Developmental care can positively impact a preterm baby’s brain development and long-term outcomes. It includes: offering unrestricted access to their baby by the parents; supporting kangaroo care; breastfeeding; noise abatement; restricting light exposure; pain management protocols; staff training on appropriate baby handling; state recognition and sleep preservation.

**Baby diary:** A simple way of documenting a baby’s progress during their stay in a neonatal care environment, a diary can be especially important during a parent’s absence. It should contain a simple summary of the baby’s highlights and key events of the day, as well as photos where possible. Hand/footprints are also good to include. Diaries should normally be instigated on admission to the unit; the diary is intended to be used by family members and staff. It is especially important if a parent cannot visit (for example because of illness, or difficulties due to childcare, or visiting a sibling in a different hospital). The same applies when a mother is unwell and is unable to visit her baby. Bad news should never be communicated via a diary.

**Journey box:** A box provided either by the parents or the neonatal unit, for parents and family members to contain the keepsakes accumulated during their baby’s stay on the NNU. It may contain anything the family wishes, for example CPAP hats, baby’s first blanket, name band, and often their journal as well. Journey boxes provide a practical way of dealing with the trauma and distress of a neonatal unit admission, as well as a record of how far their baby has come.

### 4. Parent preparation

To prepare for and minimise the stress experienced by the family when admission of their baby (babies) to the neonatal unit is anticipated. Preparation is initiated prior to admission and may take place on the fetal medicine unit, antenatal ward, delivery suite or when first visiting the neonatal unit. Following good preparation, the baby’s admission to the neonatal unit should be well managed and the family should be given all information relating to their baby and the unit.

#### 4.1 Antenatal
- Obstetric staff to liaise with neonatal staff
- Tour of the neonatal unit and introduction to the admission procedure for parents
- Provision of relevant literature prior to admission

#### 4.2 Delivery
- Member of the neonatal team to visit parents on the delivery suite as appropriate
- Provision of relevant verbal and written information
- Contact between parent and baby following delivery depending on medical condition
- Family to be aware of the admission area within the unit and be welcomed to the neonatal unit on arrival
4.3 Admission to the neonatal unit

- Provision of photo to parents (where possible prior to the insertion of tubes)
- Parents are welcomed and made to feel welcome on the neonatal unit
- Ask parents how they would like to be addressed and their baby’s name. Record baby and parents’ names on the cot card
- Identify any religious, spiritual or cultural needs that the family may have
- Volunteer an update to parents when they visit
- Answer questions (where appropriate) and refer to senior / medical staff as appropriate
- Provide information to parents on hand washing and ask them to ensure they teach their visitors to do the same
- Provide verbal and written information to parents about visiting policy, ward rounds and handover
- On admission, give each family an admission pack containing unit information, also provide Bliss admission book
- Provide car-parking permit form
- Show parents the layout of the unit including family room, expressing room, bathroom and how to enter and leave the unit
- As appropriate discuss accommodation issues with parents and involve the sister-in-charge

4.4 Transfer to a different level of neonatal care or to another hospital

- Where possible prepare parents in advance of possible transfer, use northern neonatal website for updated information for parents (http://nornet.org.uk/parent information).
- Provide parent with the opportunity to visit the area providing a different level of care or the unit they are being transferred to. This includes paediatric wards and the paediatric intensive care unit
- Differences to policy and procedures (where these are known) should be highlighted to parents prior to transfer

4.5 Discharge

- Consider the discharge process from as early as possible in the baby’s admission
- Multidisciplinary team to liaise closely with discharge coordinator
- Maintain an open dialogue with parents regarding the likely timeframe of discharge
- Organise discharge planning meetings when appropriate
- Follow unit discharge checklist and complete prior to discharge
- Identify barriers to discharge as soon as possible
- Identify and address parental concerns regarding discharge
- Involve external agencies where required i.e. social services, home oxygen, long term ventilation team, health visitor and general practitioner
- Help parents to identify sources of support within their family/community in advance of discharge
5. Parental involvement in the care of their baby/ babies

All staff work towards enabling parents to be fully involved in the care of their baby/babies. Parental involvement leads to better health outcomes. The regular and often extended periods of time that parents spend with their babies makes them experts in their babies’ personality, behaviour and wellbeing. This often enables them to notice subtle, albeit subjective changes in their baby’s condition. Staff should empower parents to relate their observations to the medical team for them to use as an integral part of their assessment. Parental involvement increases confidence and reduces stress and anxiety.

5.1 Communication

- Ensure that the parents are regularly updated by the neonatal team, in their spoken language
- A consultant should meet with parents within 24 hours of their baby’s admission to discuss their care
- Encourage a culture of trust and openness with the family, so that they feel they can ask questions as needed, thus empowering them
- Organise interpreting services as required. It is not appropriate for other family members, domestic staff or health care assistants to translate. It is, however, appropriate for other medical professionals to translate. Internet interpreting services should never be used

5.2 Practical baby care

- As soon as parents are ready, teach them how to provide practical basic care for their baby
- This may include: nappy changing, topping and tailing, mouth care, taking temperatures, bathing and dressing baby

5.3 Developmental care

- Explain the concept of developmental care to the family and how staff and the family can work together to create a positive, comfortable environment for the baby
- Teach the family how to decrease some of the stressors to the baby – light, noise, positioning, and handling and touch (refer to the separate comprehensive Network Guideline for Developmental Care and also any local hospital policies on these aspects of care)
- Encourage and support skin to skin cuddles by parents. Ensure that parents know the benefits of skin to skin care and provide written information
- Always offer standard cuddles as an alternative to skin to skin if the parent would prefer it
- If the baby is unable to come out for a cuddle, ensure parents have been taught containment/comfort holding

5.4 Feeding

- Ask parents how they wish their baby to be fed and include them in discussions about feeding
• Mothers should be taught how to hand express and thereafter provided with evidence based information and support for breastfeeding/expressing (refer to the Network lactation guideline)
• Make sure that mothers know who they can ask for help or advice with expressing and breastfeeding, e.g. feeding specialist, nurses, nursery nurses and other trained professionals
• When appropriate teach parents how to carry out tube feeds

6. Facilitate optimal bonding

Parents who have the opportunity to be taught how to interact with and care for their baby experience less anxiety and depression, have improved breastfeeding rates and feel better equipped to be a parent. Babies experience less stress and improved physiological outcomes. Optimal bonding and attachment improves cognitive and behavioural outcomes as well as neurological function and brain development. Children who have a strong attachment to one or both parents have fewer incidences of separation and attachment disorders.

6.1 Parental bonding
• Staff should make every effort to recognise the importance of parents adapting to their new role in a very stressful environment and facilitate bonding and attachment through various initiatives
• Encourage parents to talk, sing and read stories to their baby
• When appropriate, initiate individualised care/play plans. Encourage the parents to be involved in the development and implementation of these, taking into account the parent’s knowledge of their baby’s individual likes and preferences
• Initiate a baby diary when one or both parents are unable to visit for any reason. Encourage parents to take photos and keep a journal/journey box if they find this helpful

6.2 Sibling involvement
• Ask the family how the baby’s siblings (if applicable) are coping. Encourage an open (age appropriate) dialogue with their older child(ren). Suggest that parents invite siblings’ to ask any questions and answer them as truthfully as possible. Sometimes this might mean that they need to give their children permission to ask difficult questions as children often fear that they will upset their parents. Most experts agree that if children are not given enough information they tend to invent a more frightening scenario than the reality
• Suggest how siblings could be encouraged to draw pictures, read stories or choose a small toy for their baby brother or sister to promote involvement and bonding

7. Staff training and education

Family centred care improves professional satisfaction and decreases health care costs by reducing the mean length of stay. Research has shown that staff experience a stronger alliance with the family in promoting the child’s health and development, the staff demonstrate improved decision-making based on better information and
collaborative processes and have a greater awareness of the family’s strengths and care-giving capacities. There is improved patient safety from collaboration with informed, engaged and motivated families.

- Staff will attend annual training to review best practice in family centred care and share ideas
- Nominated FCC link will develop, implement and evaluate low cost strategies appropriate for the unit – such as journey boxes, journals, baby diaries and reading books
- FCC link will facilitate audit of the parent experience and establish whether there is room for improvement
- New evidence based ideas to improve family centred care will be cascaded to staff members
- Staff will collaborate with relevant members of the multi-disciplinary team and the family to ensure that the care for each baby is individualised
- Staff will make every effort to establish the individual strengths and difficulties for each family, in order to better understand their coping strategies and specific needs, as well as to provide sensitive care consistent with the family dynamics and culture

8. Consistency across the Northern Neonatal Network

Parents experience a high level of stress when moving hospital. Some of this stress can be alleviated with simple measures to inform and explain departmental and procedural differences (where known). However, some discrepancies are not based on evidence, and cause parents considerable anxiety – e.g. differences in visiting policy, policies on tube feeding etc. Consistency within the network would help to remove some of these frustrations and grievances, leading to greater patient, family and staff satisfaction.

**FCC link should be nominated in each network hospital.**

- FCC coordinator will liaise with FCC links within the network to identify what is already being done at each hospital to promote family centred care. Working together they will identify for each hospital what needs to be done in terms of collaboration, education and audit
- FCC coordinators will work with the network FCC links to facilitate consistency throughout the network (where possible)
- FCC coordinators will work nationally with other FCC posts and networks throughout the country, to cascade new ideas and initiatives to the network
- Good practice will be shared amongst the network via the FCC link nurses and the FCC Co-ordinator

9. Roles and Responsibilities

9.1 Family Centred Care Coordinator

- Provide evidence based information to family members and staff relating to family centred care
- Provide support to families and staff on the unit

Guideline for Family Centred Care 8
• Research, develop, implement and evaluate low cost strategies appropriate to the unit
• Facilitate audit of the parent experience and establish whether there is room for improvement
• Demonstrate best practice on the unit
• Liaise with FCC links to identify what is already being done at each hospital, and what needs to be done in terms of education, collaboration and audit
• Deliver regular training sessions across the network
• Liaise with other Bliss nurses and FCC links across the country to cascade new ideas and initiatives

9.2 Ward Managers
• Ward managers are responsible for ensuring the FCC Guideline is available to all members of the multidisciplinary team. They should make sure that all staff members adhere to FCC guideline
• Ensure that all staff receive annual training updates
• Authorize the ordering of Family Centred Care information leaflets which have a cost

9.3 Practice Educators (where available)
• Ensure that training is provided for all staff formally through in-service training and updates, and informal (cotside) training
• Ensure all new starters and students undertaking a placement on the NNU are aware of and familiar with the FCC guideline
• Facilitate training on aspects of FCC

9.4 Family centred care links in network hospitals
• Identify individual strengths and challenges within their specific neonatal unit
• Ensure literature is available to parents and maintain adequate stock levels
• Maintain dialogue with FCC coordinator, and play a key part in conducting audit of the parent experience
• Act as first point of contact for other staff members who have queries about aspects of family centred care
• Maintain parent display boards relating to kangaroo care, containment/comfort holding, developmental care and family centred care
• Ensure that baby diaries are being used when parents are unable to visit

9.5 Doctors, Nurses, Nursery Nurses and HCA’s
• All staff caring for parents to be familiar with and participate in the implementation of the FCC guideline
• Ensure that parents and family members are included in discussions about their baby’s care
• Volunteer updates to the family on their baby’s condition
• Demonstrate ways in which the family can care for their baby in a practical way
• Suggest practical initiatives to improve attachment and bonding
• Instigate the use of baby diaries when parents are unable to visit for any reason
• Work with parents in situations when painful procedures are necessary for babies and negotiate a mutually satisfactory compromise where parents are unable to be present
• Ensure parent information leaflets are available at all times
• Teach mothers how to express by hand or pump and be able to refer them to other staff if they require additional support

10. Dissemination and Implementation

10.1 Dissemination
• This guideline will be made available on the Northern Neonatal Network website and in the Northern Neonatal Network guideline folder

10.2 Implementation
• Actions will be taken to embed this guideline throughout the Northern Neonatal Network. Family centred care links at each Network hospital will be at the forefront of communicating and implementing it. Staff training will be undertaken during induction programmes, yearly updates and by ‘training on the job’. Practice educators will be responsible for organising this training.

10.3 Evaluation
• Audit of the parent experience will be undertaken on an annual basis in all units within the Northern Neonatal Network. The results will be presented to the Network board. Where appropriate an action plan will be formulated to address areas of concern.
• Every unit within the network will evaluate parent/family feedback
• Feedback is regularly obtained via the network and is disseminated to each of the network hospitals by the representatives at network meetings, via network website and link nurses.
References


H M Government (2010) Maternity and Early Years: Making a good start to family life, 12


### Document Control

<table>
<thead>
<tr>
<th>Document Ref. Number</th>
<th>NNNGUIDE07</th>
</tr>
</thead>
<tbody>
<tr>
<td>Title of document</td>
<td>Guideline for Family Centred Care</td>
</tr>
<tr>
<td>Original author’s name(s)</td>
<td>Sue Thompson</td>
</tr>
<tr>
<td>Author’s job title(s)</td>
<td>Bliss Family Centred Care co-ordinator</td>
</tr>
<tr>
<td>Document type</td>
<td>Network guideline</td>
</tr>
<tr>
<td>Document status</td>
<td>V.1.0</td>
</tr>
<tr>
<td>Based on</td>
<td>New guideline</td>
</tr>
<tr>
<td>Signed off by Board</td>
<td>D. Jenkins, Network Chair 24/04/14</td>
</tr>
<tr>
<td>Publication date</td>
<td>30/05/2014</td>
</tr>
<tr>
<td>Next review date</td>
<td>01/03/2016</td>
</tr>
<tr>
<td>Distribution</td>
<td>All Network Units</td>
</tr>
</tbody>
</table>

### Consultation History

<table>
<thead>
<tr>
<th>Version</th>
<th>Date</th>
<th>Consultation</th>
</tr>
</thead>
<tbody>
<tr>
<td>V 1.0</td>
<td>March 2014</td>
<td>Network Guideline Group</td>
</tr>
<tr>
<td>V 1.0</td>
<td>March 2014</td>
<td>Network Board</td>
</tr>
</tbody>
</table>