

POPPY

Parents of Premature babies Project

Family-centred care in neonatal units

A Summary of research results and recommendations from the POPPY Project



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Roles and responsibilities

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The NCT was the fund-holder and Mary Newburn, Head of Research and information, chaired the Steering Group.

Other members of the steering group were Andy Cole, CEO, Bliss, the special care baby charity; Nicola Jones, parent of a premature baby and founder member of Warwick Premature Baby Support Group; and Lesley Taylor, NCT Breastfeeding Counsellor Tutor and Special Interest Coordinator for parents of premature babies. During the course of the project Shanit Marshall-Strang and Claire Pimm represented Bliss on the Steering group.

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Executive summary

The POPPY Project involved research on three aspects of neonatal care and the provision of services that are important for the parents of premature babies. These were:

- parents' experiences of having a pre-term baby and their perceptions of the acceptability and appropriateness of the support and information they were offered;
- services and facilities currently provided for parents by neonatal units in the United Kingdom (UK);
- effective interventions for communication, support and information, as identified by a systematic review of published research evidence.

Babies being cared for in neonatal units in the UK usually receive outstanding clinical care. Less consistent attention has been paid to the non-clinical issues and how these affect a family's journey through neonatal care and their experience of the transfer from hospital to home. The POPPY Project Steering Group recommends that all neonatal units provide family-centred care.

Family-centred care in a neonatal unit involves health professionals actively considering how it feels for parents to have a premature or sick baby and working within a policy framework to improve the family's experience. This means being willing to 'stand in the shoes of parents'. It involves introducing practices and providing facilities that encourage and support parents and families throughout the care pathway. It is vital that mothers and fathers are included at the centre of the care process, alongside their baby or babies.

Interviews with parents

Interviews with 55 parents in England and Scotland indicated that periods of transition were particularly stressful times. These include the baby's birth and arrival on the neonatal unit, movements between different units or different levels of care and leaving the unit to take the baby home (see figure 1, p31). Parents valued:

- consistent, clear information about the unit and caring for their baby,
- receiving emotional support,
- practical guidance and encouragement in caring for and feeding their baby, including on-going support for breastfeeding.

Continuity of care is very important for families, particularly at times of crisis, during transitional care, and at discharge when the parents are assuming full responsibility for their baby's care for the first time.

Neonatal units survey

Neonatal units across the UK were included in the survey, to which 73% responded. A number of neonatal units employ positive approaches to family-centered care, providing:

- a playroom or area for siblings,
- the use of parent and staff completed diaries to improve communication about the baby's development and well-being, and
- one-to-one parent support schemes.

While almost all units provide comfortable chairs for parents in the different areas of care, at least one in ten do not have a parent sitting room within close proximity to clinical areas. A quarter of units had no single rooms for babies in which families could care for their baby while preparing for discharge home.

In many units, important gaps in services include:

- the lack of a service run by counsellors, psychologists, psychiatrists or social workers to provide psycho-social support for parents, and
- the lack of a unit-based family care nurse to aid transition to home care.

Half of the units had a parents' group and only a third had a one-to-one parent support scheme in their area. Over half had a home visiting scheme, and only one in six had a specialist family care nurse.

Systematic review

The systematic review found that interventions to improve the provision of information and support for parents, and to increase parents' involvement in their babies' care, can have a significant impact on parents' confidence, their parenting behaviour and the wellbeing of the family. Interventions for which there is positive evidence from randomised controlled trials (RCTs) include of skin-to-skin (or kangaroo) care, support for breastfeeding, provision of clear information about their baby's condition, and education about the baby's developmental needs and behavioural cues.

Some important findings from high quality RCTs in the systematic review are listed below to illustrate the range of interventions that can contribute family-centred care:

- an educational behavioural intervention programme can improve parents' mental health outcomes, reduce mean length of stay in NICU (-3.9 days) and total hospital length of stay (-3.8 days) (Melnik, et al, 2006);
- kangaroo care can reduce maternal anxiety, and increase a mother's sense of competence and sensitivity towards her infant (Tessier, 1998);
- at 3 months, mothers shown how to massage their infants while in the neonatal unit can be less intrusive, mother-baby interactions more reciprocal, and their infants more socially involved (Ferber 2004);
- providing audiotapes of parent-doctor consultations can improve parent recall of diagnosis, treatment, and outcomes at 10 days and four months. (Koh 2007);
- home support programmes for at least the first year, involving regular home visits to offer emotional and practical support, can reduce maternal stress and improve mothers' responsiveness to their baby (Klebanov 2001, Spiker 1993).

In summary, there is promising evidence that improved communication and involvement of parents in their baby's care is of benefit to babies and welcomed by parents. It promotes positive parent-child interaction and wellbeing. It can reduce the length of stay of pre-term infants in the neonatal unit, the need for re-hospitalisation and long-term morbidity.

Introduction

POPPY was a three-year research project to identify effective interventions for communication, information and support for parents of a premature baby. The name was taken from 'Parents of Premature babies Project – Your needs'. POPPY was a collaborative project involving researchers, third sector organisations and parents of premature babies.

Part 1 of this report provides a summary of the findings for three linked research studies.

Part 2 includes the model for family-centred care, developed by the POPPY Project, drawing on the research findings, and a list of practical indicators for the implementation of family-centred care.

Introduction to the research

The POPPY Project included three main phases of research which were developed through collaborative discussions led by researchers at the Royal College of Nursing Research Institute, with parents from the Warwickshire Pre-term Support Group, National Childbirth Trust, Bliss, other health care professionals and researchers. These discussions identified the need to focus on three main areas of parents' experiences – communication, information and support which seemed to represent the 'core' of the parent's experience. Three aims emerged from these discussions:

- identify what works: effective interventions for communication, support and information
- identify what works for parents: acceptability and appropriateness from their perspective
- identify what is currently provided by neonatal units .

Identify what works: effective interventions for communication, support and information

We carried out a systematic review of research studies which has examined parents' experiences, particularly in relation to interventions that help them in relation to communication, information and support. A systematic review provides a very thorough and robust way of searching for studies, assessing their quality and then using the results to identify which interventions are supported by research evidence. The interventions identified underpin the POPPY model of family-centred care. This review was carried out by the RCN Research Institute.

Identify what works for parents

In addition to understanding what the research literature tells us, we wanted to find out about parents' first-hand experiences of communication, information and support in the UK. We carried out qualitative research with mothers and fathers who had recently had a premature baby. Analysing the interview and focus group data provided a vital insight into both good and poor experiences and has helped us refine our model of family-centred care. This review was carried out by the RCN Research Institute.

Identifying what is currently provided by neonatal units

We carried out a survey of neonatal units to develop our understanding of what units do to support parents and to identify what facilities they provide to support family-centred care. This survey was carried out by the National Perinatal Epidemiological Unit at the University of Oxford.

Part 1

1.1

Summary of qualitative research with new parents

Individual interviews were carried out with 42 mothers and 13 fathers in England and Scotland, June 2007 - October 2008. There were also two focus groups with fathers and one with mothers.

Pre-natal

Parents' experiences:

- Parents identified a need for preparation for their time at the neonatal unit (either before their premature birth if it was expected, or afterwards if there was little warning). New fathers were often on their own when they first visited the neonatal unit if their baby's premature birth was unexpected. They found the experience shocking and appreciated one-to-one support from a member of staff at this time.
- Parents wanted health professionals to talk to them about the opportunities there would be to hold their premature baby, and to breastfeed.
- Parents appreciated the clear detailed information provided by health professionals.
- Parents reported that inconsiderate or inconsistent information on the part of health professionals, and lack of knowledge about pre-term labour or premature babies was confusing and distressing.

Helpful interventions referred to by parents:

- Parents appreciated being prepared for what was to follow. Having a tour of the neonatal unit was highly valued.
- Receiving written information about the neonatal unit was considered helpful. Often parents do not retain spoken information at this stressful time, though verbal communication and explanations were also highly important.
- Those parents expecting twins who were offered a specialised ante-natal class, or discussion with staff from the neonatal unit, appreciated the opportunity to find out about what would happen to their babies immediately after their birth.
- Parents liked being introduced to the health professionals who would be caring for their baby in neonatal unit.

Immediately after birth

Parents' experiences:

- Parents found it stressful seeing their baby for the first time. 'All the monitors and everything, it was quite scary because we didn't know what they were.'
- Several women said that their need for information, involvement and contact with their new baby in the first hours after the birth was completely overlooked. Their status as a mother and their emotional needs were not acknowledged or accommodated.
- Mothers who were separated from their babies found being with other mothers and babies on the postnatal ward very difficult. Several of the mothers said that their need to be treated with sensitivity and given emotional support when separated from their baby was not met. 'I couldn't get out of the bed and so I had to keep asking for information,

“how is he, what’s going on?”’

- Fathers reported feeling marginalised, one said ‘it would have been easy to be a visitor rather than a dad’.
- Parents said they needed information and support in order to familiarise themselves with the neonatal unit and to envisage what the future might hold; different formats are needed to meet a range of different needs and preferences, including direct conversation, written key points, detailed information packs, useful internet sites, DVDs with real families’ experiences.
- Several fathers said that their partner needed more physical care and more emotional support after the birth, and that they would like to be able to stay overnight to be with her.
- Fathers needed more opportunities to talk about their feelings. ‘We tend to be that, kind of, more macho and guarded about our emotions. There was no opportunity to deal with that other than with your family, which I think is a big void.’
- Mothers and fathers wanted information about starting to breastfeed.

Helpful interventions referred to by parents:

- Remembering back to being a new mother in the first hours after birth, women said they would have liked a neonatal nurse to contact them to inform them about their baby(ies) progress in the neonatal unit.
- Parents appreciated being given a talk or leaflet to introduce them to the neonatal unit, the facilities provided for parents, the practical help available and the purpose of the technology being used to stabilise, monitor and feed their baby.

On the neonatal unit

Parents’ experiences:

- Parents said it was important to have a good rapport with the nurses caring for their babies, and to be offered active support by them. Many felt that this was one of the really positive aspects of their care, as the neonatal nurses were often approachable, attentive and very kind. ‘They just sat and spoke to me and they just chatted. It was like they always had time for you and that, in itself, really, really helped.’
- Parents felt that communication with the doctors could be improved in terms of involving parents, the level of detail provided and the clarity with which things were explained. ‘The doctors, I always felt, were a bit removed, and I was a wee bit disappointed in that, because they would come on their ward round and they would sort of go into a huddle about him and then, while quite often they wouldn’t even, they wouldn’t actually say, unless I asked. ...They have to provide some level of feedback.’
- ‘I didn’t understand what they [the doctors] were explaining because when you speak to a doctor, they don’t speak to you like properly, ...they don’t explain... they just like put bits into the conversation and then you’re sat there afterwards and you think “well I don’t exactly understand what he said to me”.’
- Parents said that it made a big difference if they were able to develop a rapport and sense of camaraderie with other parents on the neonatal unit. ‘The six of us [parents], we were all quite similar and quite, and you started an initial conversation over washing your hands, and it grows. But I found that invaluable and just being able to laugh about things is, to complain about things, but there was not, there was nothing really huge to complain about, it was just, like, little, and I found it really invaluable.’

-
- Some units had a parent counsellor or psychologist coming into the neonatal unit regularly. Several parents appreciated the opportunity for counselling.
 - Some parents said that 'information overload' was a problem. They felt less overwhelmed if information was given little by little giving them time to take it in and process it, with regular up-dates. 'I used to ask the same questions over and over again but they'd still, you know, be patient with me because you know, obviously, they understand what you're going through.'
 - Parents found it very distressing to be given conflicting advice about how to care for their baby. At a time of vulnerability it was crushing to have followed one person's advice and then feel criticised by another staff member. Examples provided included use of dummies, exposure to day-light, wheeling babies outside in a pram while still on a monitor, and aspects of tube feeding. This indicates a need for some neonatal nurses to be more self-aware and better able to put themselves in the parents' shoes.
 - Many parents were distressed at some stage during their baby's early days by health professionals who communicated in an insensitive way.
 - Fathers found it difficult having to cope with going back to work and needing to switch off their emotions in order to function and get through the day. This was exacerbated by difficulties of getting through the security door when they were able to visit their wife and baby; waits of up to 20 minutes were reported.

Helpful interventions referred to by parents:

- Parents were more satisfied with their communication with doctors when doctors included discussion with parents in their ward round; when baby progress charts were used to assist communication; and when doctors spoke clearly, and provided explanations that parents could understand.
- Parents felt it was helpful to have access to information as and when they needed it, and available in different formats: verbal, written, web-based.
- Parents really appreciated consistent information about how to care for babies, and encouragement for expressing breastmilk and breastfeeding. Some mothers said that the positive things the staff said kept them going when they were ready to give up.
- They valued 'parent circles' for support, and both educational sessions and support groups led by a health professional.
- Parents liked seeing story boards and photo albums of babies who had previously been at the neonatal unit.
- One unit had a webcam so that parents could see pictures of their own bab(ies) when at home.
- Parents valued the opportunity to talk to a counsellor.
- Some women said that information and support for expressing breastmilk and for breastfeeding could have been better, so that they had more realistic expectations, adequate privacy and practical help.
- Some parents wanted to be introduced to kangaroo care and given support to hold their baby skin to skin as this was not offered to them during the first few days.
- Swipe cards or security codes for parents to enable them to access the security doors without delay.

Transfer between different levels of care

Parents' experiences:

- Parents reported heightened uncertainty and fear at times when their baby was transferred from one level of care to another, including moving from intensive care to special care and from SCBU to transitional care. 'I just – I was completely and utterly shocked, I was in shock, I was really upset, I couldn't understand what was going on, I had this mixed feeling of guilt – so guilty because I should be jumping around with joy, but I just wasn't prepared for it.'
- Parents said they needed but didn't always get an 'induction' when their baby was moved to a new level of care; parents felt unsettled and anxious when they did not know what was expected of them. 'Before we moved to special care we were kind of told when you come up tomorrow the chances are [the babies] will be next door so don't come along here and get a fright that they're not here kind of thing, but nobody actually sat down and said well this is the difference in special care, this is what will happen in here compared to there.'
- parents appreciated being more involved with their baby as he or she made progress. 'We were very confident handling [care of our baby] by the end of that hospital because you're doing it all the time ... and it's that much more complicated if she's in an incubator with wires on and everything.'

Helpful interventions referred to by parents:

- Staff introducing themselves to parents when their baby was transferred from one level of care to another.
- Having an introductory talk or leaflet – to explain new policies, what was expected of parents and what services were available to parents.
- Health professionals continuing to provide emotional support and support for breastfeeding. 'They [the nurses] were helping me to breastfeed and to change him and wash him and it was every 20 minutes a knock at the door, do you want a cup of tea? Do you want a chat? Are you worried about anything? It was just fantastic.'
- Use of a parents' common room. 'There was a common room and so you didn't really see much of each other because you are taken up with your baby but we would meet at meal times and have a good chin wag for 10 minutes and so it was nice to be with people in a similar boat.'

Transfer between hospitals

Parents' experiences:

- Parents reported practical 'nightmares' of transfer to another hospital. This included additional financial costs. One unemployed father was only able to visit the neonatal unit once a week and a request for overnight accommodation was refused. 'But Stuart found it really hard to come from [home town]. He only came through once a week because he wasn't working, do you know what I mean, we didn't have the money to come through. But I got help from, like, the social fund.'
- Parents found it stressful to lose the continuity of care from the previous hospital, in particular they regretted losing levels of communication and support they had come to expect from their local hospital.

Helpful interventions referred to by parents:

- Telephone follow-up from previous hospital so they still felt supported by their local hospital.

Discharge and going home

Parents' experiences:

- Parents reported inconsistent communication about when their baby would be discharged. 'One nurse is saying 2 days and one is saying a fortnight, which one is it? My partner was constantly booking days off work to come and get us and the doctor would turn up and say "oh no he is not going home today".'
- They said 'rooming in' with their baby at the neonatal unit for one or two nights before being discharged was important. 'When we were in the transitional care [the nurse] explained to me look, once you get home you'll hear her making noises that you've never heard her make, ...but you don't hear it in here because of all the other background noise, but once you're home and it's quiet and you'll get worried, but rest assured it's normal. Right enough when we got home, we were like "Oh God, is she not going to shut up?".'
- They felt that it was important to 'feel ready' for transitional care and to be supported during this period of change and new responsibilities. 'All of a sudden it was oh you are going home and ...we didn't really know what we were doing, where we were doing it or why we should be doing it. It was very strange.'
- Parents' reports suggest that discharge information needs to be improved. When both verbal and clear written discharge information was provided it was greatly appreciated.
- Parents reported the importance of having on-going support from the neonatal unit at home after discharge. Visits from health visitors with specialised knowledge in premature babies were also highly valued.
- Depressed mood or anxiety and isolation was very common for the mothers once they returned home with their babies and were on their own all day. Links with other local mothers and somewhere to go to meet other people and break up the day were considered really important.

Helpful interventions referred to by parents:

- Receiving written discharge information.
- Being telephoned by a health professional from the neonatal unit in the first week after discharge.
- Provision of emotional and practical support from a neonatal liaison nurse or a health visitor specialising in premature births.
- Training for health visitors and GPs in pre-term baby issues and the effects for families.
- Support groups and buddy schemes for new mothers and new fathers.

The qualitative research is being written up for publication in peer reviewed journals and details will be provided on the POPPY website as they become available (www.poppy-project.org.uk).

1.2

Neonatal unit survey: summary of findings regarding information, facilities and support for parents of premature babies

The aim of the survey was to answer the following questions:

1. What facilities are provided for parents in UK neonatal units?
2. What information is provided, in what ways and how is it communicated to parents?
3. Are there policies in place which aim to support parents and babies and address their needs?

How the survey was carried out

All the units in England, Scotland, Wales and Northern Ireland were sent a letter addressed to the nurse manager or senior nurse responsible for the unit, inviting participation, with a link to the online survey. Questionnaires were also provided electronically or as a paper copy on request. Data were returned between November 2007 and April 2008 on the neonatal unit environment, facilities for parents, sources of information, unit practice about informing parents and policies in relation to communication, information and support.

What we found out

Based on the 73% of units returning information, which were representative of all UK units as a whole in terms of the numbers and levels of care provided, there were commonalities and differences in the facilities and information provided to parents and in the policies in place to inform and support them.

Facilities

Some units can be quite crowded, with little privacy for parents, especially where occupancy levels are high: most Level 1 units have three or four rooms in which care is provided, though may have as many as six; Level 2 units on average have four and may have more, and level 3 units vary considerably in the numbers of rooms available. Some of the responding units have up to ten babies requiring intensive or high dependency care in one room. While big rooms may be divided into smaller areas this can still mean quite crowded environments from a staff and parent perspective. Having smaller rooms for one or two babies can provide some privacy. They can be helpful for parents prior to discharge home, for parents caring for twins, or where barrier nursing is required. A quarter of units do not have this facility.

Parents with sick and premature babies spend many long hours in the units in which their children are receiving care. Almost all units provide comfortable chairs in the different areas of care, though this is less likely in intensive care areas. Similarly parent sitting rooms, where it is possible to rest away from clinical areas, but reasonably close by have been recognised as valuable in contributing to parental wellbeing, encouraging visiting and contact, and supporting breast-feeding. Over one in ten units do not have these. While many units have facilities for parents to prepare snacks, usually near to the sitting room, approximately a quarter do not have such a facility.

Most units have a toy box and three-quarters have a playroom or area. For

parents with other young children, especially those under five, such resources may encourage visiting and assist the adjustment of other children to the neonatal unit.

Being able to stay overnight is important at times of crisis, in preparation for home and in supporting parent-infant relationships. Almost all units report having one or more rooms for parents. Slightly fewer have facilities for parents to 'room in' with their babies before they are discharged. The numbers of rooms available for parents range from 0-8 in number. The median for Level 1 and Level 2 units is two rooms and three rooms for Level 3 units. The quality of the facilities such as parents' rooms, toilets, kitchen areas, etc can vary: in half of the study the parents' rooms had been upgraded in the last three years; for one in ten the upgrade had taken place ten or more years ago; over two-thirds of rooms had double or sofa beds, over three-quarters had a facility to prepare snacks nearby, but less than a third had showers or toilets en-suite.

Half of the units had a parents' group and a third had a one-to-one parent support scheme in their area. Over half had a visiting scheme, and one in six had a specialist family care nurse.

Information

Parents with a baby in neonatal care need information about the way the unit is organised, how the babies are cared for, the different staff, explanations about equipment and the location of facilities. Most units reported antenatal visits to the neonatal unit for parents, just over one-third offered this routinely, and individual parents whose baby might be admitted were able to visit before their baby was born. Nine out of ten units or more were able to provide written or visual information for parents: a unit booklet, Bliss parent booklets, leaflets on specific conditions and a display or album with photographs of infants. However not all made these obviously available. Up to two-thirds of units, including Level 3 units, provided information on specific topics such as ventilation, phototherapy, and tube-feeding. A much smaller proportion provided information on parental reactions to preterm birth and support after discharge home. A small proportion of units presented information in a different way, such as DVDs about the neonatal unit or a unit website. Relatively few had books, DVDs or videos about the unit for parents to borrow.

Respondents were asked about how parents are given information or updated on their baby's condition and care. In about one in six units, parents were excluded from ward rounds completely. In the other units, parents were either present for the whole of the round or invited in when their baby was discussed. In two thirds of units, staff discussed their baby's care and management with parents after a ward round, including all of those units where parents were excluded from the round. Free access to an infant's notes was possible in only a fifth of units. However, when asked about other ways in which parents are updated, many staff emphasised free access to bedside notes and care plans. No units were reported to give parents recordings of consultations with medical staff about their babies and very few gave parents written update summaries about their baby's current condition and care. Information in relation to going home, specifically around safety and resuscitation, was more common than nutrition and growth, recognising when a baby is unwell, preterm development and follow-up, all of which worry

parents at this time.

Policies

The existence of formal unit policies is an indicator which reflects consideration of, and planning in relation to, family-centred and high quality care. Policies have been most commonly developed in relation to aspects of managing parents and babies that impact on the organisation and infant care from the staff perspective: more than two thirds of units had policies on parents and infection control, visiting, consent for procedures and discharge, though not all units did so. Fewer units had policies about keeping in contact with parents and parental overnight stays. Units were asked about policies relating to the support of specific groups of parents: approximately two-thirds had policies relating to parents who misuse substances; less than a fifth had formulated policies concerning the care of parents of twins and higher multiples, teenage parents, ethnic minority families and mothers with a disability.

Policies in relation to specialist staff differed. A wide range of health professionals can work in neonatal care including counsellors, psychologists and psychiatrists and social workers, but nearly half the units did not have the services of any of these professionals to provide psycho-social support. A relatively small proportion of units had a unit-based family care nurse and though specialist home visiting services were reported to be available, these may be targeted at a small group of babies considered to be at greater risk, perhaps requiring home oxygen and having other complex needs.

Key Messages

Neonatal units need to provide family-centre care. The POPPY steering group has agreed that this involves a combination of a philosophy of care that emphasises partnership working and shared decision making, a range of policies to help to ensure that information, support and parents' sense of involvement in their baby's care is of a consistently high quality, and a range of organisational features and facilities to welcome parents, respond to their needs and build their confidence. In particular, this means:

- Providing a positive physical environment for babies, parents and staff.
- Developing policies to support parental contact and effective communication with parents.
- Facilitating effective information-giving to all parents, including asking parents for feedback on what works well for them.
- Enabling parents to find the support they need from professionals and other parents.
- Focusing on bridging the gaps in care, using benchmarking to reduce variation in policies and practice and improve quality.

Levels of care

Neonatal intensive care unit (NICU) - Level 3

This provides the whole range of medical neonatal care but not necessarily specialist services, such as neonatal surgery.

High dependency - Level 2

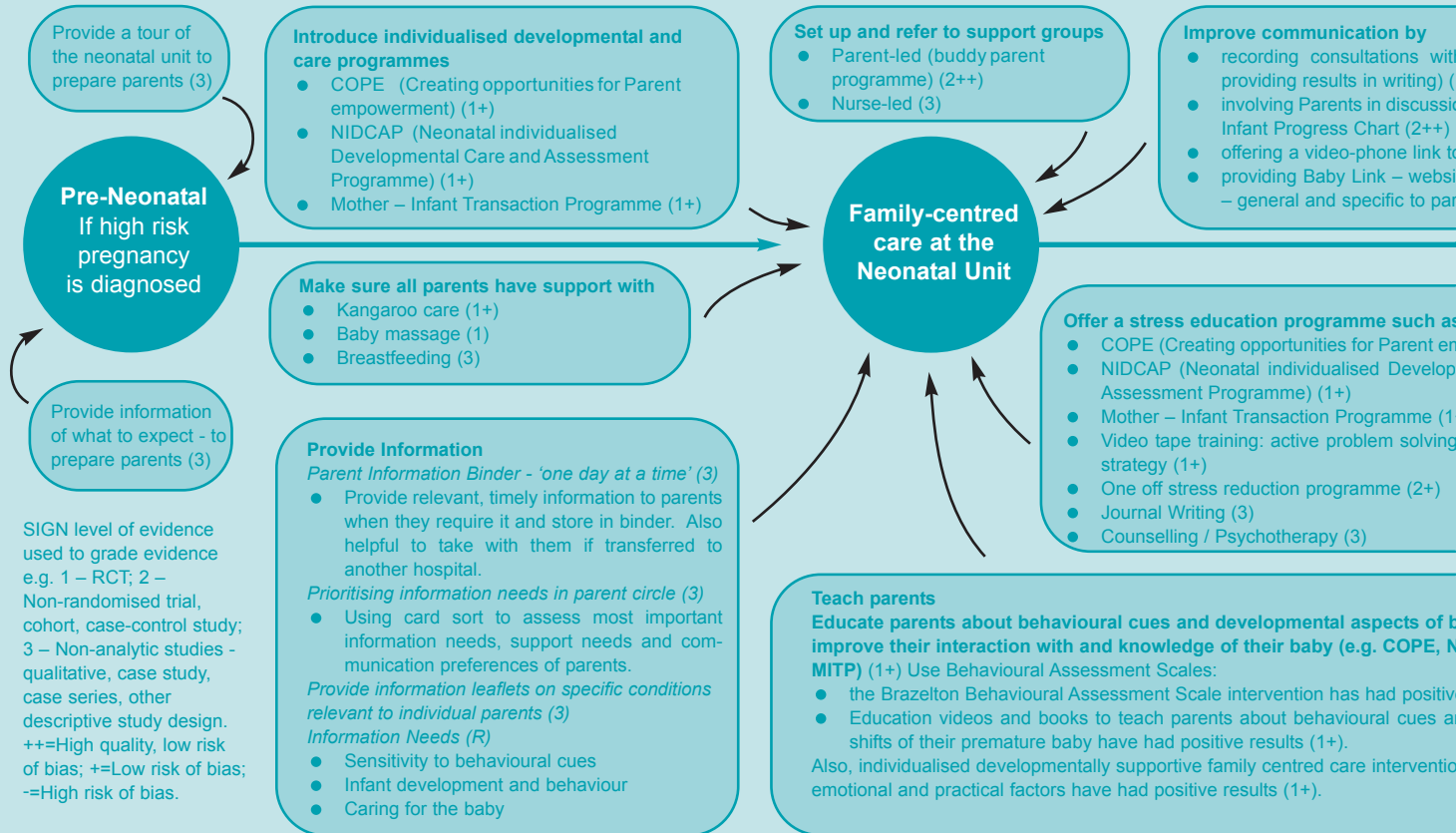
This care often involves the continuation of some breathing support and intravenous nutrition, together with some other care needs that babies may have.

Special care baby units (SCBU) - Level 1

This area is often referred to as 'low dependency'. This may involve some tube-feeding or some additional oxygen support and light therapy (phototherapy).

1.3

Summary results of the systematic review for communication, support and information



Additional notes

The individualised developmental and behavioural care programmes identified were:

- 1) COPE (Creating Opportunities for Parent Empowerment) - has provided an educational programme for parents at the neonatal unit on the appearance and behavioural characteristics of pre-term infants, how parents can participate in their infant's care, meet their infant's needs, and how parents can make more positive interactions with their infant (Melnik 2006).
- 2) NIDCAP (Neonatal individualised Developmental Care and Assessment Programme) is an intervention to stimulate pre-term infants and improve the mother-infant interaction (Ali 2003, Vander Pal 2007, Wielenga 2006).
- 3) MITP (Mother-Infant Transaction Programme) helps to enable the parents to appreciate their infant's unique characteristics, temperament, and developmental potential, sensitising parents to their infant's cues so they can respond appropriately (Kaaresen 2006, Nurcombe 1984).
- 4) NCATS (Nursing Child Assessment Teaching Scale).

NB: While the developmental care programmes are designed to improve the development of the baby, these interventions also had the effect of supporting parents psychologically, giving them practical guidance on how to care for their infants, and recognise their infant's behaviour cues.

Behavioural assessment scales

Behavioural assessment scales are designed to help parents assess and interpret the behaviour of their pre-term infant, so that they can understand their infant's cues/signals and therefore feel more confident in caring for them. For example, the Brazelton Behavioural Assessment Scale. COPE, MITP and NIDCAP also teach parents to identify infant cues as part as individual developmental care programmes (see earlier section).

The following activities help parents to feel close to their babies and need, they can increase confidence and facilitate attachment and bonding:

Breastfeeding - feeding directly from the breast or use of breast milk for tube or bottle feeding.

Kangaroo care - holding a preterm infant so that there is skin-to-skin contact between the infant, wearing only a nappy, and the parent's bare chest. It is typically practiced for two to three hours per day, over an extended time period in early infancy.

Baby massage - parents conducting baby massage on their medically stable pre-term infants to improve sensitivity and bonding between the parents and the infant.

References

This study found that it was helpful to prepare selected parents for the neonatal unit before their baby was born:

- *Preparing parents for the neonatal unit.* Huckaby 1999.

The following studies have evaluated care and information practices that have involved parents at the neonatal unit, with positive results:

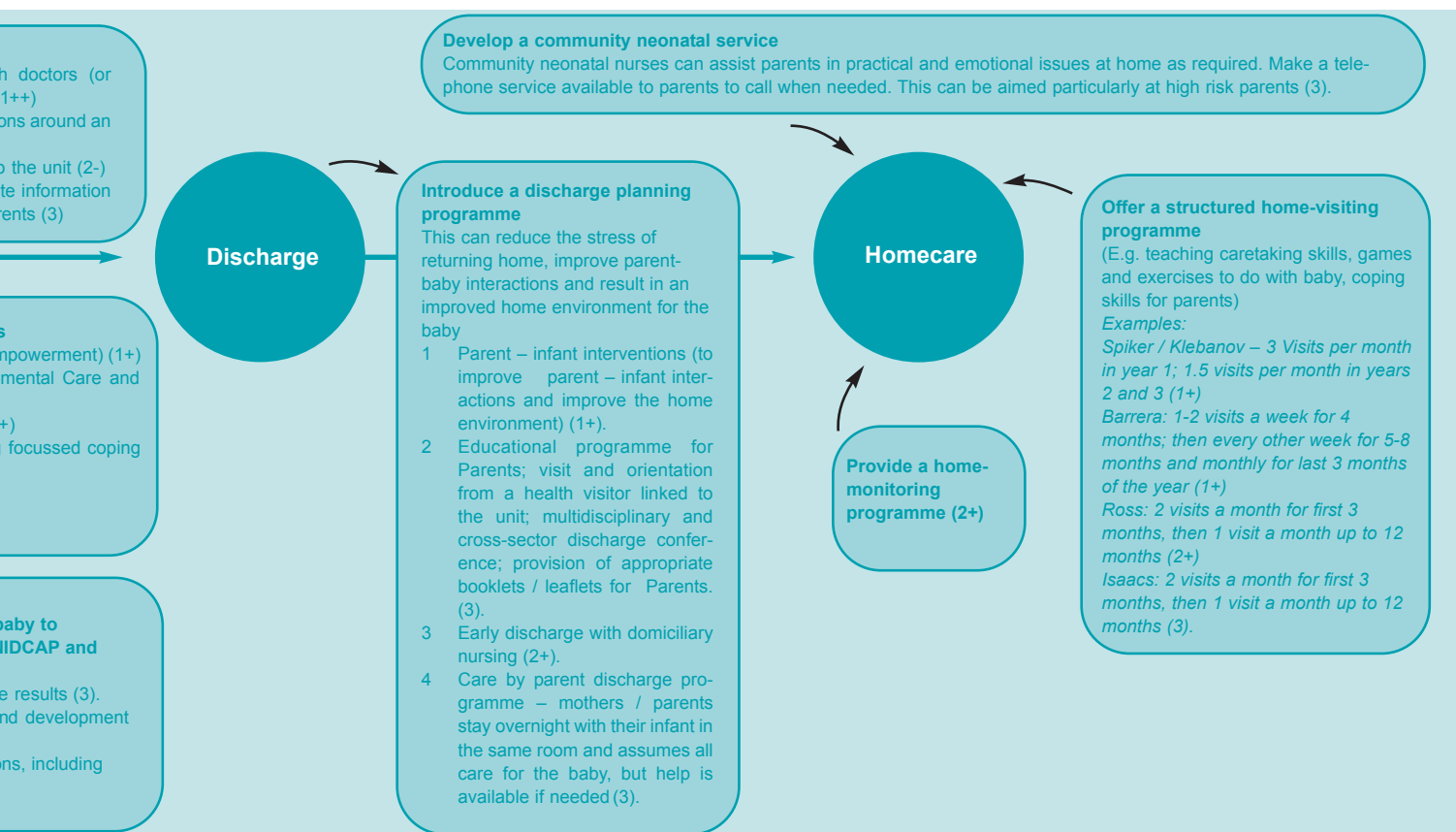
- *Provide Information.* Kowalski 2005, Gannon 2000, Costello 1996, Brown 1994.
- *Teaching parents.* Hawthorne 2005, Culp 1989, Szajnberg 1987.

Also see Individualised, developmental care programme section.

- *Support for kangaroo care, baby massage, and breast feeding.* Feldman 2002, Tessier 1998, Legault 1995, Affonso 1993, Gale 1993, Remedios 2005, Ferber 2004, White 2000, Elliott 1998, Meier 1992.

The following studies have evaluated aspects of communication with positive results:

- *Support Groups.* Buarque 2006, Hurst 2006, Lindsay 1993, Dammers 1982
- *Improve communication.* Koh 2007, Jones 2000, Gray 2000, Koh 1998, Piecuch 1983.
- *Individualised developmental care programme.* Ali 2003, Kaaresen 2006, Wielenga 2006, Evers 2006, Meyer 1994, Rauh 1990, Parker-Loewen 1990
- *Stress Education Programme.* Melnyk 2006, Cobiella 1990, Nurcombe 1984, Zuckerman 1984



A well-organized parent-to-parent support program can provide support and resources to help parents deal with the stress of having a baby in the neonatal intensive care unit (NICU). Research findings show that parents can benefit from a range of different kinds of support:

- a health professional-led support group at the neonatal unit to teach care, give emotional and practical support, answer questions etc.
- a parent to parent 'peer' support programme - buddy parent programme where 'experienced' parent is matched to parent at neonatal unit
- parent-led support groups (outside of the neonatal unit).

Parents seem to benefit from discharge programmes

Discharge programmes are designed to prepare the parents of pre-term infants for going home and coping at home without the expertise of the health professionals constantly available. Some discharge programmes are also developed to allow the able parents to return home with their pre-term infants early.

Home support programmes show benefits for parents. A number of different models have been evaluated positively:

- In two studies parents are visited and given emotional and practical support 3 times a month for the first year after discharge, and 1.5 visits per month in years 2 and 3 (Klebanov 2001, Spiker 1993).
- One study evaluated home visits by a health professional for 1-2 hours once or twice a week for the first 4 months, every other week for next 5-8 months, and monthly for the last three months of the year. (Barrera, 1986).
- Another model was for parents to be visited twice a month for 3 months after discharge from the NICU, and then once a month for up to 12 months after teaching mothers caretaking skills, games, and exercises (Ross, 1984).
- Another study involved a neonatal nurse or paediatric occupational therapist visiting parents twice a month for 3 months after discharge and then monthly up to 12 months. The parents were taught caretaking skills, games and exercises to facilitate cognitive, motor and social development in their infant (Isaacs – case series).

Effects of support at the neonatal unit with positive

006, Preyde 2003, Pearson 2001, Bracht 1998, Roman
es 2007, Kowalski 2005, Freer 2005, Penticuff 2005,
ammes. Van der Pal 2007, Glazebrook 2007, Melnyk
Browne 2005, Ali 2003, Prentice 2004, Lawhorn 2002,
1987, Affleck 1986, Nurcombe 1984, Byers 2006,
2006, Kaarensen 2006, Jotso 2005, Ali 2003, MacNab
eanah 1984.

The following studies have evaluated interventions involving educational packages or additional support at time of discharge:

- *Parent-infant interventions.* Barrera 1986
- *Educational programmes.* Broedsgaar 2005
- *Early discharge with domiciliary nursing.* Ortenstrand 2001, Jonsson 2003
- *Care by parent discharge programme (Transitional care).* Bennett 2005, Costello 1998.

The following studies have evaluated support services in parents' homes with positive results:

- *Structured home visiting.* Klebanov 2001, Finello 1998, Swanson 1997, Spiker 1993, Resnick 1988, Ross 1984, Isaacs 1980
- *Home monitoring programmes.* Kurz 2002, Leonard 1989
- *Community neonatal service.* Langley 1999.

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Part 2

2.1

Focus on families: family-centred care in the neonatal unit

The context

Modern neonatal care is a specialist service and an integral part of maternity care, with one in nine babies admitted to a neonatal unit. Although technological and scientific advances have progressively reduced neonatal morbidity and mortality, less attention has been given to meeting the psychosocial needs of the baby and family. The neonatal environment is designed for efficient technological care and may not be optimal for nurturing the growth and development of sick newborns or their families. Parents whose babies are admitted to a neonatal unit are likely to be facing a difficult and often unexpected situation which contrasts with conventional postnatal care and transition to parenthood.¹ Their initial and subsequent experience is characterised by stress and uncertainty and by concerns about longer term outcomes for their baby. Participation in making decisions and caring for their child is often limited.

Within the past decade, family-centred care has become a broadly accepted concept within neonatal and paediatric intensive care. Both professional and user organisations are promoting the need for integration of family-centred principles into standard practices and guidelines. Parent-focused and family-centred services, in which parents receive appropriate information, support and effective communication, are integral elements in the 'individualised, flexible care' described in the National Service Frameworks and Clinical Standards documents.²⁻⁵ In England, the Department of Health implementation plan, 'Maternity Matters', places women and their families 'at the centre of the provision of woman-focused, family centred services'.⁶ Engagement with these principles is required at all levels within the NHS. Specific goals and aspirations that have been put forward include the following:

Services should take full account of individual needs, including language, cultural, religious and social needs.⁶

- Women should receive co-ordinated postnatal care.... with an agreed pathway of care, encompassing both medical and social needs, including the care of their babies who may require neonatal services.⁴
- High-quality communication between professionals, women and their families, and between professionals and colleagues, must be central to the provision of excellent maternity care.³
- Maternity services are delivered in partnership with women and their families and strive to ensure safe and positive outcomes for women and babies at all times.⁵
- Wherever possible, separation of mothers and babies is avoided by nursing babies who require additional care with appropriately trained staff on the postnatal wards.⁵

What is family-centred care?

There is a growing body of literature on family-centered care, to which the POPPY study is contributing.^{7,8,9} Family-centred care is a philosophy of care which helps families whose infants require hospitalisation cope with the

stress, fear and altered parenting roles that may accompany their infant's condition and hospitalisation. Family-centred care has been associated with infant benefits (lower behavioural stress cues and comparable short-term outcomes, shorter lengths of stay, fewer readmissions, enhanced breastfeeding,¹⁰⁻¹⁵ increased staff satisfaction as well as a positive impact on stress levels, comfort level and parenting confidence of NICU parents and families).^{10,16,17} In addition, family participation in infant care leads to greater family satisfaction with the health care experience.^{17,18} Ultimately, family-centred care may enhance attachment between an infant and the family and result in improved long-term outcomes for both.¹⁹

In this context, family-centred care is about health professionals considering how it feels for parents to have a premature or sick baby needing to be cared for in a neonatal unit, and working within a policy framework to improve their experience.¹ This means being willing to 'stand in the shoes of parents'. It involves introducing practices and providing facilities that encourage and support parents and families throughout the care pathway. The care pathway includes several phases of care in different settings and lasting for variable periods of time (see Figure 1, page 31). In broad terms these phases are 'preparation', 'intensive care', 'special care' and 'care at home', though for individual families the pathway may be more complex involving, for example, transfer between different hospitals. It must also be recognised that not all babies make linear progress through the pathway. There may be temporary set-backs in health requiring a return to more intensive care, as well as babies growing and maturing. Sadly some babies die or have long-term health problems, so some parents need bereavement support or continuing counselling, and specialist support.

Services should ensure that there is integration of information, communication and support between intensive, acute and community care settings. It is important to respond to parents' perceptions of their needs during each phase of care and particularly during periods of transition. Family-centred care is characterised by the following broad principles: parents and families are treated with dignity and respect; health care providers prioritise open communication and sharing information with parents and families in ways that are affirming and useful; parents have a right to know about their baby's care and condition and full updated information should be available to them; information-giving is tailored according to parents' individual preferences for detail and their changing needs; parents and family members are encouraged to participate in their baby's care with the aim of them developing a sense of confidence, control and growing independence; practical and emotional support is provided continuously, throughout the care pathway.²⁰

Key elements of family-centred care for premature babies and their families are listed in the box below.

- Recognising and valuing the roles of parents, siblings and other family members.
- Developing awareness of parents' needs, the emotional impact of preterm birth and individual differences in parental responses and needs.
- Recognising critical steps for parents on the care pathway.
- Maximising opportunities for communication with parents and local community groups.

- Providing practical help with infant care and parent interaction, including behavioural cues .
- Increasing confidence in role as a parent and supporting the parent-infant relationship.
- Providing psychosocial support.
- Valuing and supporting mothers' ability to nurture their baby through expressing breastmilk and breastfeeding.
- Providing appropriate family-friendly facilities .

These elements emerge as important from the literature and the three phases of POPPY research.^{7,8,9} The POPPY findings provide recent evidence and insights that are directly relevant to current healthcare policy and commissioning in the UK.

Why is family centred care so important for parents of preterm and sick infants?

Pregnancy and childbirth provide a valuable window of opportunity to make a difference to the wellbeing and future of babies and their families. In the context of a start in life that is not straightforward, becoming and being a parent can be difficult. In a fundamental way, supportive and high quality care can help equip mothers and fathers with the skills to be confident and caring which, in turn, will have the potential to improve outcomes for the whole family.

What do parents need and how can family-centred care meet these needs?

To get to know their baby

Establishing a relationship with your newborn baby is a two-way process that takes time. Access and contact are essential for parents, together with an appreciation of the way a baby's medical problems and gestational age may be affecting their behaviour and development. The nature of the relationship changes as a baby matures and individual differences and responses, which are so important to parents, become more obvious. Experienced and skilled staff can support the developing relationship directly with practical help in facilitating contact and in exchanging information with parents. Evidence suggests that talking to parents about their baby's instinctive behaviour, adaptive responses and possible vulnerabilities, using a structured approach such as the Brazelton Neonatal Behavioural Assessment Scale, can increase their confidence in interpreting behavioural cues and their sensitivity towards their baby.²¹ As well as enhancing parent-infant interaction, a recent randomised controlled trial of the COPE educational-behavioural intervention program (Creating Opportunities for Parent Empowerment) improved parent mental health outcomes and reduced both mean length of stay in NICU (-3.9 days) and total hospital length of stay (-3.8 days).²²

Emotional Support

In neonatal care the focus is on the baby and parents appreciate the emphasis on addressing their baby's medical needs. However, the baby's future life and development will take place in the context of his or her family. Worries and concerns during pregnancy and the crisis nature of the birth of

a preterm or sick baby can, for many families, create considerable distress and uncertainty. When admitted to the neonatal unit, parents' immediate needs primarily relate to emotional support. The need for this kind of support is likely to persist throughout a baby's neonatal stay and during the early months at home.

Involvement in care and decision-making

The model for the relationship between parents and healthcare professionals should be one of equals, with staff respecting parents' unique role as the baby's family and aiming to enable them to be fully involved with their babies' care. Some clinical decisions will be made when there is no time for explanations or discussion, or when the parents are not present, but every effort should be made to keep parents informed and to consult them. It should be remembered that the baby is born into a family and the neonatal unit is working for the baby's health and wellbeing and for the wellbeing of the whole family. Practical support and involving parents in their baby's care assists confidence building in the early days and can give some measure of control when a parent may be feeling powerless. As babies grow and milk feeding is established, opportunities for parents to care for their baby increase and begin to prepare for going home. Practical support is particularly important during times of transition and when parents are expected to take increasing responsibility in caring for their still small and vulnerable baby.

Parents' closeness and involvement with their baby can be supported through encouraging:

- positive reassuring touch
- comfort or containment holding
- skin-to-skin or 'kangaroo' care
- nappy changing and providing other care
- expressing breastmilk
- giving milk feeds.

Effective communication between the family and the health care team

Parents' needs for effective and timely communication are diverse and may fluctuate according to their baby's condition. Sharing information should be seen as a two-way process including parents' feelings, wishes and observations about their baby as well as information from health professionals. There is much to discuss, such as the baby's care; the facilities in the neonatal unit; the parents' role in care; next phases of care e.g. moves within the neonatal unit, transfers to another hospital, timing of discharge home and what the future may hold for them and their baby. Enabling parents to ask questions and discuss concerns is key to supporting current and future wellbeing and avoiding miscommunication. Ensuring consistent information is important, as conflicting messages can undermine parents' confidence and the sense of them and their baby receiving high-quality individualised care and support. Translation services must be available for key consultations and written information provided in a range of languages. It is good practice to ask parents to repeat what they have been told, to check whether they understand (feedback from Yana Richens, member of the POPPY Research Advisory Group).

Family-friendly facilities in neonatal care

Appropriate facilities for parents and families in or near the neonatal unit will enable parents to visit, stay during the day and to feel welcome in doing so. It is important for mothers to have good facilities to enable them to express breastmilk frequently and feed their baby, both in a comfortable, private room but also by their baby's incubator or cot, as they may want to stay close to their babies and close proximity enhances the let-down reflex. Availability of milk from a human milk bank is important especially for families with twins or more babies, for mothers who are too ill to express or babies undergoing surgery and likely to need expressed milk.²³

Siblings should be able to visit and parents be able to stay overnight with a reasonable degree of comfort and privacy. When parents first visit a neonatal unit, when their baby is admitted and when moved to a less intensive level of care, e.g. special care, they need to be shown around, told about the facilities and what they can do for their baby, and how to get additional support if they need it. Written details of the facilities should also be provided (available in different languages) so that parents have information to refer to later.

Support at times of transition, including going home

Parents interviewed for the POPPY study made it clear that times of transition, including being admitted, moves between units, changes to less intensive care, and when leaving the unit to go home, were difficult for them. There was disruption to the reality they were used to and new challenges to face. Significantly at this time, there was often a change of staff, and a perceived lack of information and support. Leaving the neonatal unit is both a positive and a frightening step for many parents and families. The proximity of medical and nursing care and the established relationships that have developed while a baby is in a neonatal unit contribute to feelings of safety. Facilities in which parents can stay overnight and room-in with their baby before taking them home provide an important transitional environment. A gradual approach with shared planning and preparation for discharge is needed to support parents in taking on the full responsibility for the wellbeing and care of their baby. Later follow-up at home is also important. The availability of outreach support over the early weeks at home, and longer for babies with specific medical problems, is an invaluable way of providing the practical and emotional support needed at this important time. Acute and community sector health services should work with children's centres and third sector organisations to develop networks of community support with in-reach to the neonatal unit.

Whose responsibility is it to enable family-centred neonatal care?

- All healthcare professionals working in neonatal care and those working with babies and their families after discharge home.
- Individual practitioners, with specific roles and duties e.g. breastfeeding support, home visiting, bereavement care.
- The organisation (PCT, board, hospital trust and individual unit) responsible for providing care, with parent and family oriented policies, training and education.
- Neonatal networks and other organisations or groups commissioning and

planning the provision and organisation of care.

To what extent is family-centred care embodied in current policy and practice?

A wide range of formal and informal interventions have been recognised as helpful in supporting parents in different hospitals at different times as shown by the POPPY systematic review and the qualitative interviews. These include parent-to-parent support schemes, specialist health visitors and neonatal unit outreach care. Trust and unit philosophies often use the language of individualised and family-centred care, however, studies indicate an inconsistent application of family-centred care in everyday practice and variation in perceptions of the essential elements.^{24, 25} The data collected in the POPPY survey of UK units shows considerable differences in unit layout and facilities, generally unrelated to unit size or level of care, and variation in policies relating to parents that are supportive of individualised and family oriented care.

What is needed to ensure that all neonatal units provide family-centred care?

In order to ensure that all services provide family-centred care there needs to be a commitment to this approach throughout the entire maternity and neonatal pathway. As well as considering how the services are experienced by babies, their parents and wider families, it means becoming a learning organisation in which there is regular communication to share ideas across multi-disciplinary teams, policy guidance, research findings and feedback from local parents is used to facilitate learning and service development. Resources need to be available for:

- improving facilities,
- sufficient staffing of direct care and support (including support workers and outreach working),
- staff input to policy development,
- staff training, and
- preparation of information materials for parents and families, including ensuring that information is available in a variety of formats and languages so that it is widely accessible.

Having the opportunity and sufficient time to listen and talk is critical in providing a high quality neonatal service for babies and their families today and in the future.

In summary, the quality of what is provided for parents and their experience of neonatal care is highly variable. Neonatal units differ in terms of the kind of babies cared for, the facilities for parents and families and the policies in place. While many units and maternity services feel that they already provide a service that is family centred, the variation between units and different parts of the country and parents' accounts of their experiences suggest that an explicit commitment to family-centred care is required. This will require a review of funding for direct services, facilities, training, information provision and outreach work. We are asking for a renewed focus on ensuring that communication is of a consistently high standard, improvement in facilities and even more effective engagement with parents both in the unit and in the early months at home.

Figure 1:

Family-centred care in the neonatal unit and afterwards

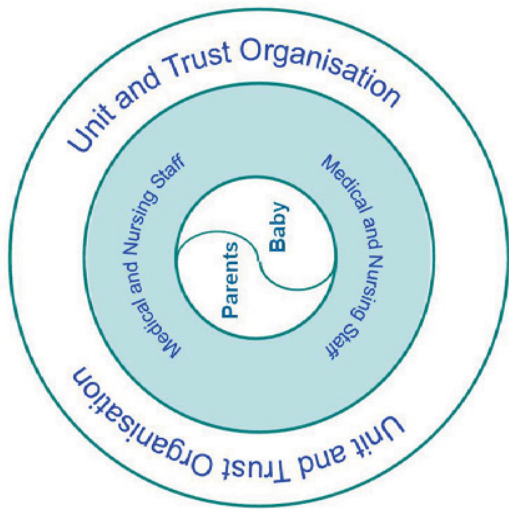
Role and identity as a parent intrinsically involves:
protecting + nurturing the newborn

BUT Admission to neonatal care is associated with

- Separation
- Marginalisation
- Lack of responsibility
- Loss of nurturing and protective role

Neonatal care with a family focus aims to minimise adverse effects with:

- A family-centred care philosophy
- Family-friendly facilities
- Development of specialist roles
- Family oriented staff training and support



Parent Pathway

Preparation - before admission to the neonatal unit	Admission to the neonatal unit	Early days in intensive care	Growing and developing	Transition to care at home
<p>If planned</p> <ul style="list-style-type: none"> • Visit to unit and/or 'virtual' tour • Contact with neonatal unit staff • Discussion before transfer <p>If unplanned</p> <ul style="list-style-type: none"> • Basic information in labour and delivery • Information about possible transfer if required 	<ul style="list-style-type: none"> • First visit to unit by one/both parents • Introduction to staff and the environment • Parents given key information and unit contact details • Possible overnight stay for mother / father / partner 	<ul style="list-style-type: none"> • Getting to know your baby, unit staff, care patterns and routines • Contact with baby regular and without constraint • Mother needs postnatal care • Involvement in care • Mother fully supported to express breastmilk and put the baby to the breast as soon as possible • Other family members introduced/give support 	<ul style="list-style-type: none"> • Increased responsibilities for parents • Building confidence based on own experience and helped by skilled staff • Moving out of intensive care • Learning from the experience of other parents • Other family members visit 	<ul style="list-style-type: none"> • Discharge planned • Overnight stays with baby by one or both parents • Follow-up arrangements made and contact details provided • Outreach arranged and links made with outreach staff and health visitor • Adjustment to taking full responsibility at home • Support from health visitor needed



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2.2

Indicators for the implementation of family-centered care

Neonatal units need to provide family-centre care. This involves a combination of a philosophy of care that emphasises partnership working and shared decision making, a range of policies to help to ensure that information, support and parents' sense of involvement in their baby's care is of a consistently high quality, and a range of organisational features and facilities to welcome parents, respond to their needs and build their confidence.

The following indicators are intended to provide practical guidance.

Philosophy of care and vision

- Positive acknowledgment that the baby is part of a family and that parents and babies have emotional and social connections that need to be respected and nurtured, particularly when babies are sick or when a baby dies.
- Unit policies which emphasise 'partnership working' with parents and families, reflected in shared decision-making.
- Openness and involvement of mothers, fathers, partners and families in providing direct care.
- Parents need access to written information about their baby's condition and frequent opportunities for discussion, with terminology explained, and checking that parents' understanding is consistent with what staff intended to communicate. These should be available in a range of formats, e.g. large print, and translated into a range of languages.
- As parents take on more responsibility for looking after their baby, they need to be supported.

Organisational features

- Open visiting: full parent participation in care requires unrestricted access to the neonatal intensive care unit. The shift from considering parents to be "visitors" to being partners in caring for their child is more difficult for units with restricted visitation policies.
- The use of specialists and the development of specialist roles funded and/or organised by the neonatal unit. Examples include breastfeeding and bereavement support, and outreach by staff with neonatal training.

Specific policies

Family-centred policies are needed on:

- introduction and orientation to the unit for parents and families;
- supporting parental contact, including engagement with fathers and partners and skin-to-skin or 'kangaroo', care;
- supporting breastfeeding, provision of breastpumps and access to donor breastmilk;
- exchanging information with parents, good practice includes parent folders, parent update meetings, baby-logs and diaries;
- preparation and planning for transfers between levels of care and discharge home;
- contact with and use of staff in specialist roles;
- access to social and psychological support, including counselling and local parent support groups.

Facilities

Facilities that can make a positive difference to parents' experience of neonatal care include:

- enough single/double cubicles for rooming-in with one or two babies;
- well-designed transitional care facilities, where care is provided by the mother and/or rooms in which parents can get used to looking after their baby prior to going home;
- care areas designed to provide privacy and minimise disturbance; e.g. rooms with six or fewer cots, space between cots and/or screening facilities;
- a parents' sitting room on or adjacent to the neonatal unit;
- a facility for parents to make hot snacks and drinks;
- a play-area or room for other children in the family;
- enough overnight rooms for parents for the size of the population served, with en suite facilities, available within the unit or a short walk away.

