

3. Infant and Family Centred Developmental Care Toolkit: Partnering with Families

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For use in: EoE Neonatal Units
Guidance specific to the care of neonatal patients.

Used by: This guideline is intended for all healthcare professionals and staff working within the neonatal unit. The principles outlined should also be shared with parents, supporting a collaborative approach to caring for premature or unwell infants.


Key Words: Family Integrated Care (FICare), Parent participation, Parent-infant bonding, Psychological support, Developmental care, Psychologically informed care, Attachment and bonding, Parent empowerment, Peer support, Education and empowerment.

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Introduction

There is overwhelming evidence which supports the understanding that parents' presence on the Neonatal unit and partnership in the care of their baby is an essential component of delivering quality developmental care and improving developmental outcomes for infants. ^{1,2}

In 2005 Bliss published seven statements that encapsulated the care, respect and support that the most vulnerable babies should receive. Following this, a framework for practice has been further developed using the core principles of family-centred care and has now become a nationally recognised tool for neonatal services to measure, develop and improve their family-centred care practices. This is known as the [Bliss Baby Charter](#).

Evidentially, the most effective initiatives, aimed at supporting parent participation in their baby's care, have required systemic changes to the neonatal care culture and have included the entire health care team with commitment from the leadership team and organisation. ⁴

In the UK, the impact the environment, culture and organisational components has in supporting and empowering families is now understood and recognised within a further framework - Family Integrated Care (FICare).

Family-Integrated Care

Family integrated care (FICare) is a collaborative model of neonatal care which aims to address the negative impacts of the neonatal intensive care unit (NICU) environment by involving parents as equal partners, minimizing separation, and supporting parent-infant closeness. FICare incorporates psychological, educational, communication, and environmental strategies to support parents to cope with the NICU environment and to prepare them to be able to emotionally, cognitively, and physically care for their infant. ^{2, 5}

A model of Family Integrated Care practice has been proven to be effective in:

- Reducing mortality and infection
- Reducing Parental Anxiety & Stress
- Increased participation in breastfeeding
- Increasing infant weight gain
- Reduced length of stay
- Reduced readmission (BAPM 2021)

FICare is recommended as part of the Neonatal Critical Care review (2019) and subsequently the NHS Three year delivery plan for maternity and neonatal services. With support from the charity Bliss, The British Association of Perinatal Medicine (BAPM) have produced a guidance document: ['Family Integrated Care: A Framework for Practice'](#). ⁷

The document describes the key components of the five FICare principles and provides practice examples of these. This document should be used to support the implementation of FICare within Neonatal unit in the East of England.

Within the ethos of a FICare model, and alongside the Bliss Baby Charter, UNICEF have produced a [UNICEF UK Baby Friendly Initiative](#). The staged accreditation programme's standards enable units to audit current practice and guide service development in order to support families with feeding and help parents build a close and loving relationship with their baby. *See also **Optimising Nutrition** resource.

The East of England ODN recognises the importance of units meeting the standards of the Bliss Baby Charter and UNICEF

Changing culture and roles

Family Integrated care means not just physically involving families, but equally importantly changing the culture and relationships with staff. FICare requires a change in professional roles, particularly in transitioning from direct nursing care roles to 'becoming a mentor, teacher and friend'.³

This paradigm shift in culture is often the most challenging aspect of introducing and maintaining FICare; everyone within the service, from the clinical leads and matrons to the housekeepers and porters should be empowered and educated to support this change. (BAPM 2021)

Psychological Support and Psychologically Informed Care

The importance of considering the psychological impact of the experience of a neonatal admission on the baby and family has been highlighted in recent years within a number of reports, including the Ockenden report, the Kirkup report and the three-year plan for joint working across maternity and neonatal settings²³

The neonatal unit has been described as 'akin to a trauma centre for all participants' – the baby, parents and the staff who look after them. Prematurely born infants have "premature" parents who are usually unprepared for the crisis of having their newborn in the NICU. The psychological consequences of a neonatal stay for parents are extensively documented in the literature with high rates of traumatic stress, anxiety, depression (far above the already elevated rates of these difficulties in the perinatal population) and they experience a range of specific psychological difficulties that arise during and after admission that are unique to the neonatal experience. The House of Lords Preterm Birth Enquiry (2024) further illustrated the profound psychological impact on parents caring for their preterm baby on a neonatal unit which extends beyond the point of discharge and the findings from the EXPAND study* (2025) have shown significant and enduring distress a year or more post discharge. There is also a significant impact on infants longer term who are at risk of a broad range of psychological, emotional, cognitive and developmental conditions.

Psychological support should be available to all families on the neonatal unit, regardless of gestation of their baby, type of birth or level of obvious distress. Good psychological support *includes the entire neonatal workforce* and is enacted in every interaction staff have with an infant, their parents and the wider family, and all units should be working towards psychologically informed care (See https://acpuk.org.uk/wp-content/uploads/2022/09/Psychology_Staffing_on_the_Neonatal_Unit.pdf)

Families continue to be at risk of difficulties which impact their well-being and functioning, including ongoing mental health difficulties in both parent and child post discharge and psychological support should continue at discharge and be part of a seamless service [^]. ²²

Health care professionals can access specific free training to support their knowledge and become psychologically informed practitioners: [NHS Learning Hub:Psychologically Informed Neonatal Care](#)

[^] Details available in the following document (link immineint) ` Neonatal Psychological Professionals Staffing Standards: Recommendations for Outreach and Follow- Up (2025)

Peer Support

Further evaluation of the benefits of peer-to-peer support and support from veteran parents is recommended. However, common themes are that this provides a positive impact in supporting parents through neonatal experiences whilst on the unit and post discharge. Parents felt that they were able to be honest, gained confidence in caring skills and found support through `normalising` shared experiences.²⁵

Peer to peer support is often incorporated within unit led parent support programmes but can also be led by a Parent Advisory Group (PAG) member. There are specific support groups targeting families who have specific circumstances and/or diagnosis for example (but not limited to):

[Sands | Saving babies' lives. Supporting bereaved families.](#)

[Peeps HIE Charity | HIE Awareness & Support](#)

[TOFS | OA/TOF Support – Charity offering lifelong support for those born unable to swallow](#)

Recognising and supporting the individual needs of families

The East of England Neonatal ODN advocates due regard to the needs of different protected equality groups that access services within our network (Equality Act 2010). We recognise the importance of providing inclusive and

respectful information and taking in to account individual needs of parents and families.

Supportive measures should also recognise the impact of the perinatal experience on families, acknowledge individual circumstances, their ability to manage stress, grief and loss, be mindful of [hidden disabilities](#) ^{20,21}, and how they can be supported to access information and resources.¹

Supporting attachment and bonding

The attachment and bonding process is acknowledged to start pre-birth, during pregnancy. The event of a premature birth and separation of a baby (including a term baby needing medical care) and their parents is seen as a traumatic event which impedes the natural physical close contact that a baby and their parents require which can cause 'long-lasting effects on emotional programming, neurodevelopmental outcomes, and parental mental health'. ^{13,14}

The relationship between parent-child attachment and developmental outcomes is well understood and for the very preterm infant, this parent-child relationship begins in the NICU. The relationship is established and developed when the parent is present in the NICU, holds the infant, and learns how to identify and respond to the needs of the infant. ¹⁹

Particular support to facilitate bonding, despite obstacles posed by the infant's neurobehavioral immaturity and medical challenges, is required. This involves:

- Providing education and informational support
- Facilitating early, frequent, and prolonged skin-to-skin care ¹
- Promotion of emotional interaction and supporting understanding of infant behavioural communication ¹³

Supporting parents to understand their infant's behaviour and to respond to them appropriately, encourages the feeling that the infant "belongs" to them and therefore has mutual benefits ¹³

Supporting the understanding of infant behaviour

It is now recognised that approaches of care that are performed 'with the baby', understanding their behavioural cues and individual needs, and making sensitive and responsive adjustments in care, are the most developmentally supportive. ¹⁵

This understanding originated from 'The neuro-behavioural synactive theory of newborn development' and forms the basis of **the Newborn Individualised Developmental Care Assessment Program (NIDCAP)**.

Key principals of the NIDCAP programme are that:

- Infants are considered individuals, persons, collaborators in care, supported and nurtured by their parents.
- Parents are considered infants' key nurturers, advocates and caregivers as well as collaborators in care decisions.

- Healthcare Professionals are partners in care with infants, parents and family members.

Knowledge of infant behavioural cues and responsive care giving is mandatory for professionals directly caring for infants and their families in the Neonatal unit. (See Individualising cares- behavioural cues section).

All parents should be guided to observe and understand their baby's unique behavioural cues as soon as possible after the neonatal admission. This will enable them to offer sensitive caregiving, build their confidence as their baby's primary caregiver and support the parent-infant relationship.^{17,26}

Supporting a parent to understand behavioural cues should continue throughout their NICU journey. When a baby reaches 37 weeks gestation trained practitioners can further support families using the **Newborn Behavioural Observation (NBO)**. The NBO is a tool which helps demonstrate the abilities of newborn babies in the first 3 months of life (post term). It is a strength-based tool designed to help parents and practitioners observe a baby's behaviour. These observations can then be used as a platform for discussion and knowledge sharing. [Brazelton Centre UK – Understanding baby behaviour](#) The Brazelton Centre have also produced educational resources explaining new born behaviour (translations in multiple languages available).

Education and Empowerment for Families

There are recognised challenges for parents to be present on the Neonatal unit and in participating in the care for their baby.^{8,9} The FICARE culture aims to address some of these barriers through a supportive and environment and culture. From point of admission parent education is central to family integrated care in order to empower parents with the skills and knowledge to be primary carers.⁶ Efficiently and effectively educating families in the NICU setting can also be particularly challenging.¹⁰ Whilst standardisation of education programmes can improve the consistency of information delivered it is important to recognise different learning styles and the ability of parents to take on board new information.

Education should be multi-level offering families the opportunity to access resources in their own time, receive cot side support and attend informal education sessions/peer support.

Education should be delivered across the multi-professional group recognising the skill set that other professionals have in building confidence through coaching and mentoring approaches.⁹

Education should not just target the parental role on the Neonatal unit but should support families through to discharge and provide anticipatory guidance to support the long-term development of their child and the knowledge of resources and support available. Education, coaching and mentoring of parents is a significant element of early intervention (EI). Literature examining the best approaches of EI is rapidly growing. However, there is overwhelming consensus that a critical element to the success of these approaches are the involvement

and support of parents, not only to ensure sustained effects throughout childhood, but also because of the beneficial impact on parental wellbeing. ¹²

Core developmental topics for education may include (but not limited to):

Understanding the Neonatal environment

Principles of developmental care

Infant behavioural cues and communication

Managing your baby's pain and discomfort

Positive touch

Supporting sensory development

Positioning and handling your baby

Skin to Skin education benefits and practicalities

Supporting baby's feeding journey

Development of feeding skills

Individualised infant cares Nappy change, Bathing, Weighing

Psychological education- making sense of emotions, normalising feelings

Activities to support baby's development

Awareness of 'safe sleeping' in preparation for going home

Signposting to appropriate evidence based education resources

(Shared during EoE ODN evidence discussion and focus session)

Resources to support practice:

[Bliss Resources for Parents](#)

- About Neonatal Care
- Look at me - I'm talking to you
- Being involved in your baby's procedures
- Skin to skin with your premature baby
- Weaning your premature baby
- Caring for your baby when the future is uncertain
- Going Home from the Neonatal Unit

[East of England Neonatal Parent Portal](#)

The East of England Neonatal ODN have produced a parent portal. This is a web based platform to enable parents to find out information, share experiences and

ideas and get involved in future projects with the aim of improving parent engagement and co-production of service improvement initiatives.

Additional resources alongside support from other healthcare professionals to support parent education on the Neonatal unit and in preparation for discharge these include:

- Caring for your baby on the neonatal unit – A parents’ handbook (Warren and Bond 2014)
- [IFDC - Integrated Family Delivered Neonatal Care](#) Parent App.
- [Small Wonders | Best Beginnings](#) – Parent education videos
- [Little Journeys App](#)
- Vcreate: [A secure, multi-language video diary service for Neonatal Intensive Care Units](#)
- [Getting to know your baby](#) TVW Neonatal ODN Parent leaflet (18)
- [How Your Baby Communicates: electronic version – Brazelton Centre UK](#) available in multiple languages.
- [My First Language Booklet – Brazelton Centre UK](#)
- [The PAC project - PAC Study](#) Prematurity and Communication, collection of research and resources.
- [Sensory Beginnings Resources](#) to support a nurturing sensory environment.
- [DadPad Neonatal- Neonatal Guide for New Dads](#)
- Your Preterm Baby’s Care and Development at Home – A parents’ handbook (Warren and Pantelides 2023)
- [EI-SMART](#) Evidence based framework and resources

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