



Chapter 1. Introduction to the Integrated Family Delivered Neonatal Care programme

Parent educational material for app

Imperial Neonatal Service, Imperial College Healthcare NHS Trust

1. Introduction to the Integrated Family Delivered Care programme

Firstly, let us welcome you and your Baby to our neonatal intensive care units.

As your Baby is admitted to one of Imperial's neonatal intensive care units (NICUs) (either in Queen Charlotte's & Chelsea Hospital or in St Mary's Hospital), we know that this may be a very challenging time for you. Your Baby might be looked after in a different neonatal unit, and this App still could be useful on your journey.

The neonatal team at Imperial College Healthcare NHS Trust is strongly committed with a shared vision to provide excellent, family-centred, caring and compassionate care for our premature and term babies and their families. Excellent quality of care, honesty, privacy and bringing babies and families together are our core values.



Our units provide care to high-risk, often critically ill neonates, and **family integrated care** is one of our guiding principles and has now become standard of care in our units. The overarching goal of **family integrated care** is to **support parents to become equal members of the neonatal team and participate in providing active care for their infant with the help of this care package including a competency-based training.**

The **Integrated Family Delivered Care Programme** has become standard of care in our neonatal units. Once your baby is medically stable, you may consider participating in this project.

You are encouraged to be an active and equal member of our team in the care of your Baby. We believe that even the best medical care cannot replace your presence and the love you can provide to your Baby. Our experience and existing medical evidence suggest that your active participation can improve your Baby's outcome, and may shorten length of stay in the hospital beside other additional benefits.



Our aim is to work in partnership with parents to create a consistent and nurturing environment where they feel engaged, enabled, educated and empowered as the primary caregivers to their baby. We believe parents are experts in their baby's care.

This app and educational material was designed for our Integrated Family Delivered Care Programme, but even if you are not able to participate in this new care model it can help you a lot on the way. In this curriculum, which consists of 15 chapters, we have included useful knowledge about neonatal care.

We hope that with this material we can help you to prepare for and engage in this journey, and understand what is happening to your Baby.

Aims of this chapter

We want you as a parent to:

- understand the benefits of family integrated care models both for you and for your Baby
- learn how you can engage and participate in your Baby's care
- be aware of our curriculum and our parent educational material which can be a great help during your journey.

1.1 Having a premature baby in the neonatal intensive care unit with the support of Integrated Family Delivered Care

Katie is one of our veteran parents who participated in the Integrated Family Delivered Programme from the very first day. Her baby, Constance was born at 29 weeks.

"Our integrated family care was established at birth with thanks to the fully committed and skillful neonatal team at Queen Charlottes and Chelsea Hospital.

Our little baby Constance was born at 29 weeks gestation after my waters broke following a complicated twin pregnancy. We were lucky enough to be allowed skin-to-skin in theatre directly after our C-section. This initiated an otherwise more difficult bond between the baby and I, since I wasn't physically able to visit her in NICU until the following day. We had 5 minutes of precious skin to skin - I got to connect with her despite the ventilator and wires and cradle her into my chest - a natural feeling for a mother and a memory that I will always cherish. I am sure it also helped my body to more quickly tune in to what had just happened - my colostrum began to do its stuff and enabled me to



hand express enough to support Constance in NICU from the outset.

My husband couriered the syringes of liquid gold up to our baby until I was strong enough to meet her the next day. The advice and support we were given from the IFDC team from the outset ensured connection, excitement, love and hope prevailed. I downloaded the IFDC App which proved to be a complete life changer - I had all the information and advice I needed at the click of a button plus an easy place to store updates and information on our baby.

We began to feel part of the team of doctors and nurses looking after Constance - every decision was put by us and we always had a choice with regard to her care, having been given all the knowledge we required to make sure it was an informative one. Initially I was daunted by seeing our tiny baby in the incubator, covered in wires and tubes with incessant alarming and beeping going off from all the machines in her room. All I had to do was watch and learn from the devoted nurses who treated her like any other baby - talking to her, singing to her, stroking her and sharing information about her habits with us - they made an otherwise abnormal situation seem completely normal to us.

As I got stronger, they began to teach me how to do Constance's cares - I was patiently and gently shown how to change her nappy in the incubator, how to clean her fragile body, how to get her out safely to have skin to skin and how to tube feed her. They gave me the confidence to be a mummy and a nurse at the same time and I began to feel empowered rather than frightened. As breast feeding became established, I had a lactation consultant's devoted support and encouragement which is the only reason why I am still breast feeding her as I write this! It's a tough gig - pumping all the milk mechanically until your baby is ready to attempt feeding directly from your breast.



I could never have got through those weeks without the lactation support and general interest and encouragement from the doctors and nurses in NICU - special connections were made with everybody who treated our baby - they looked after her and me every day - not only did I have my own new family, I also had a NICU family. Integrated family care on another level.

I am passionate about the care we were shown and really hope as many mothers, fathers and babies as possible can have similar. With the right tools and the best support I truly believe the NICU journey can and should be a rewarding one for every parent. THANK YOU IFDC - YOU'RE AMAZING!!!!

1.2 Integrated Family Delivered Care in 3 words

We asked parents to summarise IFDC in three words. In the image below, you can see the parents feedback about this new care model. The size of the word corresponds with frequency of words recorded.

Integrated Family Delivered Care means:



1.3 Background to family integrated care – values and outcomes

The evidence for family integrated care goes way back to 1979, when a shortage of trained neonatal intensive care nurses in Estonia prompted Adik Levin to implement a 'Humane Neonatal Care' model, in which parents provided nursing care for their infant (except for administration of IV fluid and medication), while nurses provided teaching and guidance to parents.

This unexpectedly resulted in improved outcomes: improvement in weight gain, reduction in infections, reduction in NICU length of stay, reduction in nurse utilisation and overall improved satisfaction among parents and staff.

Prof Shoo Lee from Canada closely investigated this Estonian model and felt that this type of care could be delivered and be similarly effective in more developed countries. A pilot cohort analytical study in 2011–2012 from a Canadian neonatal unit at Mount Sinai Hospital, led by

Prof Shoo Lee, has shown that establishing family integrated care within neonatal intensive care, in a multicultural Western country, is possible. Infants born at 35 weeks' gestation or less with a parent willing and able to spend eight hours or more a day with their baby were included in the study. Prof Lee's team found it reduced the measurable degree of stress in parents. Veteran parents and medical and nursing professionals designed the parents' training curriculum with the help of allied health professionals. Soon after the infants were considered medically stable, the parents were trained with the training curriculum designed and delivering care for at least eight hours a day. This initial study showed that parents felt included in the neonatal team as equal members.

Subsequently a large clustered randomised controlled trial has been completed in 16 NICUs across Canada and Australia to evaluate the efficacy of the family integrated care model. This study published in 2018 have demonstrated improved weight gain and reduced parental anxiety and stress levels. Similar models are currently being trialled in China, Europe and the US.

This evidence shows that integrated family delivered neonatal care is possible and that clinical outcomes are better than in traditional healthcare settings. Family integrated care (FIC) programmes have shown decreased parental anxiety and depression; increased parent-infant bonding; higher breastfeeding rates and improved infant health. Weight gain improved and there was a possible reduction in infections. The total length of stay in the neonatal unit also decreased following use of family integrated care. Other studies have shown that exposing infants to meaningful speech and music therapy might improve their general wellbeing and development.

A parent's role in their baby's development is vital. When a baby is in the womb they are hearing their mother's voice and experiencing her being close through touch and smell. After they are born this closeness remains very important. The feeling of being loved and cared for helps babies to feel secure and attached to their caregivers and respond better to stress. Being responsive to your Baby's needs and providing them with care and comfort helps with bonding. The hormone oxytocin released through these experiences helps build important connections in a baby's growing brain and has a long-term impact on their development through to adulthood.

Our team established links with the Mount Sinai Hospital's team to learn about their experiences and how they deliver this new care model. Following this our team designed our own material and tools for this programme.



1.4 Aims and outline of our Integrated Family Delivered Care programme

Our service had a vision to be a pioneer in piloting this care model in the UK, and now has established this as standard of care in our units.

We would like to improve parent experience and parent-infant bonding, parental mental health and infant health outcomes by pioneering this new care delivery model.

During the last five years our team worked hard to create this app and our competency-based training material, together with veteran parents, which is the basis of our programme.

Veteran parents who have extensive experience of the Imperial Neonatal Service helped us co-design the project. We believe veteran NICU parents bring a wealth of wisdom and expertise developed through personal experience and this has helped us to design and implement this project. Our veteran parents have been actively involved in the grant application process and conceptualisation of the project.

We defined our values in our logo: we want to educate, engage, empower and enable you to be expert in your Baby's care.

The levels of activity and tasks you can do at the bedside depend on your Baby's gestational age. Following our **Developmental timeline** can give you some advice on how you can participate in your Baby's care.

This **curriculum** with 15 chapters gives you basic information about neonatal care. In addition to this, one-to-one and small group teaching sessions are available to attend. If you wish to participate in this new care model, we will help you to complete our competency-based training once your Baby is medically stable.

Parents who are trained will be the primary caregivers to their baby under supervision of the neonatal team for at least six to eight hours every day, except for administering medications and procedures. They will also help train newly enrolled parents, and will have the opportunity to attend two or three small group exercises weekly. Parents are welcome to attend and present their baby on the ward round as equal, integrated members of the neonatal team with the support of our nurses.



Educate Engage Empower Enable

Our app additionally gives you the opportunity to chart expressing, skin-to-skin cuddles and feeding progress as well as record events, pictures and memories to share with others and for the future.

1.5 Why IFDC? More for our parents about IFDC

'Baby H arrived at 26wks, 14 weeks early. She was so tiny, we were so scared. My husband and I didn't have a clue what to expect and what to do, she looked so fragile and had so many tubes and wires attached to her. The first few days were a bit of a haze, the NICU nurses took care of everything. But as the days rolled by they encouraged us to get more involved with her cares, and spoke to us about how we could connect with our baby girl even though she was in an incubator. It was a gentle, hands-on education - something we were scared to do - we always felt it best to leave it to the expert nurses and staff - but they taught us to be the experts in caring for our precious baby with confidence. We're so grateful to them for guiding and supporting us every step of the way. They would patiently answer the same questions over and over. The parent classes were always really useful and informative; cares for baby, positioning, bathing. We had an opportunity to meet with specialist fields; consultant, psychologist, pharmacist, dietician, lactation. Thanks to the IFDC programme we soon stopped feeling helpless and instead felt really empowered. The team not only listened to us, they genuinely valued our input and observations of our baby girl to help tailor her care. By the time we transferred back to our local hospital, we felt really positive and confident about caring for our baby- even the staff could tell there was something different about us!'



'Family support and hands on approach has been really good.'

'We have enjoyed playing as active a role as possible in caring for our child. We are confident and able to perform all cares and tend to all our child's needs. The nurses caring for our child have been amazing and very supportive in the whole and encouraged and empowered us with confidence, skills and knowledge to provide the best for our child. We have found the information received very good and felt we could speak to specialists early and confidently.'

'The attention that staff has been giving is individualised and unique and makes parents feel welcome, confident and comfortable. There are no words to describe the quality of the care provided. In our home country, that is not enough equipment and technology to support a baby like ours. We are really grateful for the support from doctors, nurses and other support team. Everyone has been extremely helpful. The hospital seems like a school that enable us to look after our baby at home. The whole experience seems like a dream to us.'

'Some of the nurses are amazing and so kind. They really understand our concerns and make us feel involved in her care. The doctors are great, they are always happy to answer questions and you can see how much they love their jobs. IFDC coordinator has been great, it is fantastic to have someone we can go to ask questions. We really feel like she is on our side. The ward round on a Wednesday is really great. It gives me the opportunity to explain my feelings or concerns and I know the right people are listening and my message isn't getting lost or not listened to.'



'Where do I begin. When we arrived in the unit on 15th March, it is fair to say we were terrified. The care our baby and ourselves have received has been incredible. The medical team have kept us fully informed, the nurses have a real personal quality, and the support staff, including IFDC coordinator, help you feel normal in such difficult circumstances. We will always be indebted to you for the exceptional care we all received.'

'Bedside care has been really important for us and allowed us to bond with our baby'

'Great to be able to care and bond with the baby when it is not possible to pick up the baby in the same way you would with a term baby. We got involved with the cares, feeds and skin to skin and really got to understand our baby'

'Helped me interact with my child. Fights depressive emotions'

'When I could not do the cares on my own like changing her nappy at first, they were always kindly available to show me how best to do it. This not only has helped me in gaining more confidence around my daughter but also in bonding with her even more'



'So much is medical and due to the isolating nature of the incubator, being able to do cares and feeding became a great means of bonding and feeling a part of my baby's development/ healing process'

'It made it easier to connect to my baby when she was unwell and fragile'

'Inclusive participatory approach was highly appreciated. Extremely helpful for parental stress management and baby bonding'

'Being shown how to care for my daughter whilst she was wired up allowed me to still be a mum and do what I felt was my 'job' rather than sitting back'

'Being involved in her care through IFDC allowed us to have contact with [baby's name] and feel like parents'

'The project made a difference on my stay here. It has given structure to my journey'.

'My IFDC experience has been one of the most amazing in my life, as I have learned about the value of compassion, emotional support, and empowering families to the healing process. The workshops and parents groups provide great support emotionally and in up skilling parents to take more control over cares'

'The app is fantastic; especially for tracking expressing and breastfeeding...Everything I'm told by the doctors can go in one place. The library is great too, lots of my questions have been answered without relying on Google! I also note down questions I have so I don't forget to ask them, there are lots of questions you think of at all hours of the day and night and I always have the app with me'

'The app is fantastic as a reliable source of information'

'The app was also really relevant as I could educate myself while my baby was sleeping'.

Finally,

Daniela is one of our veteran parents participating in the development of the Integrated Family Delivered Care Programme. Her baby, Milo, was born at 24 weeks, and they spent nearly six months in hospital.

She wanted to share a message with you at the beginning of your journey:

'Trying to describe the experience of having a baby in the neonatal unit in intensive care is very difficult. I thought I had time to prepare for it as I knew my baby was likely to be born very early, but the truth is that it is impossible to prepare... everything was just so different from how I imagined it.'



Milo was born at 24 weeks and had a very long journey in the neonatal unit, first in intensive care then in low intensity care. He stayed in hospital for over five months and it felt like forever. I saw most of the other mums coming after me and leaving before me, and that was tough. The hardest part though was seeing my son going through daily examinations, x-rays, blood tests, having a ventilator for two months, going through several surgeries, getting so puffy that he was unable to open his eyes.

Although it was very painful to watch, I could not be anywhere else but beside him. I often skipped breakfast and lunch because I just could not leave him. One nurse one day told me that it would have been good for me to go shopping and take my mind off, but at that time for me it was unthinkable. It was hard enough to



leave my baby at night; can you imagine going shopping? The only thing that made me feel better was being with my baby, watching him and caring for him, that's what I wanted to do and that's where I felt I belonged.

At the beginning it was exciting but also kind of scary and I needed the nurse to give me exact instructions, but the more I was involved the more things I wanted to do. I grew confident that I was able to care for my baby in the same way a nurse could. Doing kangaroo care was something I just loved. Unfortunately, I was not able to do it as much as I would have liked, because my baby was so unwell and unstable, but once he was stable enough, after a long time, I would hold him for hours. It was the time when I felt closest to him and when I could really look at him closely and smell him. At night before falling asleep I needed that image of him in my arms.

Of course, after a few months there were some other things that I really enjoyed doing with my son such as breastfeeding – very hard – but being able to feed him from my breast was great and how I always imagined it. Weighing him, putting on an outfit that I bought for him, bathing him... all things I had to wait a while before being able to do. Maybe because of that it made it even more special.

Throughout my baby's stay in the neonatal unit I met some amazing mothers: strong, determined and very resourceful. It was just really good to talk and perhaps share thoughts and feelings with them... There was a very special sense of empathy amongst mothers and it made the journey in the neonatal unit more bearable and less isolating.

As for the Integrated Family Delivered Care Project I think it is amazing and something I would have certainly done if there had been the chance when my son was born. I really think it does empower parents in their role; it does make them feel part of the team and allows them to become the experts of their baby from the very beginning.'



Key messages and reflection:

After this chapter you should be able to:

- understand the value your presence and involvement can deliver to your Baby
- be familiar with our Family Delivered Care project and its values
- decide if you wish to participate in our Family Delivered Care model

Further learning in this topic

If you wish to know more:

- make sure you attended our Parent Orientation session after the admission of your Baby
- read the curriculum chapters
- think about how to plan your daily routine on the neonatal unit, complete daily care plan for each day
- ask our neonatal team at any time
- ask for one-to-one support from one of our Family Delivered Care project nurses
- use this app or your parent binder to record notes and questions
- attend small group teaching in topic: **Introduction to Family Integrated Care.**

Authors

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