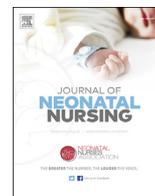




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The neonatal parent experience: How IFDC can help

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Introduction

No parent when imagining their pregnancy and delivery of their newborn baby wishes to be separated after birth, but this is what happens to many new parents of sick and premature babies. One in nine babies born in the UK will be admitted to a neonatal unit for specialist care.

There are now numerous reports describing and reflecting on the neonatal parent experience and the significant psychological consequences of admission to the NICU for both the parent and baby (Obeidat et al., 2009; Aagaard and Hall, 2008). There is an increase in incidence of stress (Yaman and Altay, 2015; DeMeier et al., 1996), anxiety and depression (Miles et al., 2007; Vigod et al., 2010; Hynan et al., 2015) for mothers and more recently the impact on fathers too has been highlighted (Pace et al., 2016; Chinn et al., 2011). The psychological wellbeing of a mother influences the parent child interaction and can impact the social, emotional, behavioural and cognitive development of children short and long term.

For all women the transition to motherhood and bonding is a gradual process that happens after birth. Mothers in NICU can have problems transitioning to the role of motherhood due to the environment and experiences they have there (Shin and White-Taut, 2006). There can be a significant impact of separation, and a potentially toxic impact of the stress it causes, to the baby and their parents if physical and emotional closeness is not considered (Flacking et al., 2012; Bergman, 2015). Bonding requires proximity, reciprocity and maternal commitment that can be compromised by admission to the neonatal unit. Separation results in reduced opportunities for bonding and can impact this developing relationship potentially impacting on maternal responsiveness, confidence

and sensitivity in the future (Sanders and Buckner, 2006; Klaus and Kennell, 1976; Feldman et al., 1999; Brockington et al., 2006; Borghini et al., 2006). The infant's emotional and behavioural development can suffer in the absence of social connectedness (Sullivan et al., 2011).

Separation along with inconsistent caregivers, repeated painful procedures without environmental support and a sensory environment that overwhelms the immature brain are potential toxic stressors for hospitalised infants (Sanders and Hall, 2017). The primary relationship to buffer the baby's response to stress should be with the parents but they need support not to be overwhelmed themselves.

Providing neonatal care is also an emotional challenge for the healthcare professionals with a fine boundary between the personal and professional interaction of caring. Everyone benefits when staff recognise that their own relationships with babies and families requires person to person attunement to provide the best neurodevelopmental care for the newborn (Adler, 2012). The importance to parents of the significance of staff going that extra step and providing respectful loving care is common in parent experience literature (Gallagher et al., 2017).

Parent experience

During our work with families in neonatal care in our service we have always tried to make sure the voice of our families experience is heard loudly and used to help up reflect on the environment and care we are giving. It is through involving parents as partners in care that we can achieve the best neonatal outcomes.

For our staff education on communication with parents we used a framework of themes of parenting occupations in the NICU that have emerged from synthesis of literature (Gibbs et al., 2015) to help draw attention to what a parent may be going through and therefore how best to communicate with them. What will they be able to think about and hear? What is most important for them to hear? These themes are described below along with quotes from NICU parents. We also show staff videos of parents' experience (<http://www.neonatalbutter>).

The origins of parent quotes where asterisked* are referenced in full from article by Gibbs et al. on parent experience (Gibbs et al., 2015). All other quotes are from our parent group.

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Relinquishing the anticipated role of parents.

A baby's admission to the neonatal environment can be a shocking and frightening experience for parents.

"It's all the beeping and strange equipment ... it's all so overwhelming. And it's not what you expected or dreamed of. I mean nobody wants that you know"

For most this was not what they imagined early parenthood would look like.

*"I've lost the chance to look after my baby, to do the things that it's usually the norm with most mothers ... bring a baby home from the hospital right away ... and show them off to the world ... I've lost that chance"**

Feeling vulnerable and powerless

Their babies are often very sick or fragile; requiring medical support and interventions. They may be separated in an incubator or connected to breathing equipment and monitors making picking them up and cuddling them difficult. They may need tube feeding and are not able to feed from the breast or bottle yet. This environment can leave parents feeling helpless, out of control and scared.

"I wasn't there so much. I lay in the maternity unit in my bed. I wanted to see him but at the same time I didn't because I didn't want to get attached. I thought he would die and I had to be prepared for that."

For parents, neonatal care can arouse deep emotions and anxiety; they can feel a lack of control and helplessness at their baby's cot side. Stress can be detrimental both to baby and parents and their developing relationship.

They may feel like they have failed as parents and this can lead to high levels of postnatal depression and post-traumatic stress for mothers and fathers. Siblings and grandparents are often limited in the time they can spend with the new baby and this can be an anxious and difficult time for the whole family.

Reclaiming an alternative parental role, adapting to parenting and coming to know the baby

Interventions are required to help parents feel closer to their babies in neonatal care. Supporting and nurturing the parenting role in this situation is vital to enable bonding and prevent longer terms problems of anxiety and trauma. Even in these early days babies know their parents voice, smell and touch and are soothed by their loving presence. It is essential to the baby's care and outcome that their parents are with them as much as possible getting to know them and do as much of their care as possible. This is important for them to reclaim an alternate parenting role:

"I felt like a true mother. Before he was so small and I couldn't handle him. I knew I was his mother but now I was doing everything a mother is supposed to do and once I started doing all that it was more real."

Getting the first relationships right is crucial to later outcomes.

Babies who have strong bonds with their parents have better neurodevelopmental outcomes (Reynolds et al., 2013).

"Being more involved was as close as possible to what I had in mind of being a mum. It enables me to bond and feel well attached to him".

"They can hear you and they know you are their Daddy. Every story you lovingly recite, every song you softly sing, every time you tell them how your day went – they are listening and will absorb your love and energy. You have no idea what an important thing this is. Don't think it's a waste of time, but instead, think of it as parenting, which it is".

Developing partnerships with staff

However even if our care is developmentally supportive and family centred, parents can still be left feeling unconfident in their babies care and excluded from their true role as parents; of being the people who know their baby best and are ultimately responsible for them as their parents. Relationships between parents and staff require respect and support and ultimately seeing parents as true partners in their neonatal care.

"Parents on the neonatal unit feel helpless and more like a spectator than a carer. We felt every health professional knew our son better than us, and bonding was difficult. This planned project really puts not only babies but babies and parents at the centre together. We would have liked to have more options and choices around his general care."

The relationships between staff and parents are vital to ensuring good communication and care. The unique role of the parents needs to be recognised and respected.

"Everything depended on what nurse you had; how quickly in the shift we could in here and develop a rapport with her, and how controlling they were".

Parents have shared the importance of feeling part of the neonatal family where everyone is transparent and trusted. Just as in other families it is a relationship of honesty, trust and vulnerability for all members equally. This was particularly noted on ward rounds where parents were made to feel part of the horseshoe around their baby and contribute to the decisions being made. Parents found this experience empowering.

"Being asked 'what do you think?' made you feel like a parent".

Some parents reflected on the magnitude of feeling they had when they realised they had influenced a decision made about their baby feeling they had when they realised they have a tranthor child. They also appreciated the honesty and vulnerability to admit that decisions are not always black and white and, despite not having medical training, their opinion as parents was equally essential to care. Parents often appreciated the honesty when a professional admitted they didn't often appreciate being able to hold that uncertainty together with the parent.

"Being part of the team, getting to do his cares has helped me observe him closely and get to know him well. I can talk to Drs in other families now, as I know him best. I getting to do his cares has

heed the reports I have everything you need. I know how to observe him and what to watch for."

Professional communication can sometimes be to present the worst-case scenario over and over thinking the parent is not hearing or understanding creating a manmade dip in their coping. Instead it may be helpful to ask them what they understand about the situation in their words and wonder with them out loud about how they feel their baby is doing.

"Facts and outcomes are important but sometimes it is helpful to believe that miracles can still happen."

Navigating environmental boundaries and juggling roles and responsibilities

Preventing separation of mothers and their babies, keeping them in skin-to-skin, providing comfort, soothing and interaction appears to buffer the potential toxic effects of stress improving outcomes and helping the development of coping strategies; reducing depression, anxiety and post traumatic stress. This model of care is not new, it's intuitive and what parents want to instinctively do when supported and given the chance.

"Having spent 14 weeks in hospital ... I hope that I will have gained experience and insight that you can draw on. Jessica received outstanding care at both units but I knew it was time for her to go home when I started thinking that she would get better care at home, as she would be on a one-to-one with me 24/7."

No doubt these feelings would have started earlier if 'Integrated Family Delivered Care' had been available when I was on the unit.

It would have offset a lack of confidence, due to her being so tiny and having been cared for by professionals for so long, along with becoming somewhat institutionalised."

We understand and believe that even the best medical care cannot replace a parent's presence and the love they can provide their baby. Working in collaboration with veteran parents has given us an opportunity to co-design the parent education programme and particularly the mobile parent app based on their feedback.

"It is a lovely way to record the moments and memories especially when there is nothing you can take inside the ward other than your phone. I tried keeping a written journal but gave that up very soon, as I had to wait till I get to the parents' room before I could do this and these obviously could not be attached to photos. I think the app will let parents capture their truest emotions in real time and the value of this in the later years when their babies can look back and see their journey is priceless, what a life story work that will be!"

Parent experience of IFDC

A Dad's diary ...

I'm Martin a normal hard working 32 year old man and proud Father of Finnley born at 24 weeks and 6 days weighing 750 g [Fig. 1](#).

Stephanie (my wife) and I were very excited at the forthcoming birth of our first child due on the 11th July 2017. On Sunday the 26th March my wife came home from church in a lot of pain, at this moment I thought we were losing our baby. We went to the hospital and a midwife examined Steph; I remember seeing blood and I've never felt so scared, the midwife said Steph was delivering our



Fig. 1. Finnley born at 24 weeks.

son. I remember saying 'no we can't as he was too young'. Within moments there was a room full of strangers, Finn's heart rate had dropped and they had to perform an emergency caesarean, I couldn't believe it as I watched my wife pushed into theatre, I watched my son been put into a plastic bag and my wife passed out, at that moment I thought I had lost everything. I met an incredible nurse who reassured me and introduced me to my son, Finn had tubes and wires coming out of him, she explained to me what the machines were doing and that we were going to be transferred to another hospital and there was a team on their way. I took some photos of the gorgeous little boy and a priest baptised our son. I remember feeling completely broken.

When I was brought into the intensive care unit, I had no idea these places even existed, it was like been on set for an end of humanity movie, I cannot explain the intensity of the place. [Fig. 2](#).

I sat there for the next 23 days and 24 nights I stayed with Finn for 19 h a day never leaving the building, the beeps of the machines, noise of suctioning and heat will never leave me, I willed Finn on, I never cried in front of my wife but every time I went to the toilet I would cry my heart out, I was scared. I can remember the doctors and nurses coming around and they would list out the problems, this would happen twice a day at handovers -the list got longer and longer, I questioned was this cruel and what quality of life would our son have?



Fig. 2. Finnley.

I was invited to join the Integrated Family delivered neonatal care programme; all of a sudden we were a part of our son's care and not just visitors, we were no longer sat on the side-lines. The medical team taught us how to care for our son and we had a real purpose; we were able to bond with our son and not just look at him in a plastic incubator. Prematurity - this was not my world but it is a part of our world now. Using the IFDC app which I was able to read about our son's development and what to expect, I found the app great especially for my wife as it kept her busy and was a real topic of discussion. Being a part of our son's care gave us everything back.

Over the coming weeks we watched as our son grew and get stronger, with every machine removed it meant if we did have a set back at least we had somewhere to go. I spent the first seven weeks expecting to be told our son had died every hour. I slept with the phone under my ear and panicked when I went away from Finn's side. During our time we met nurses, Doctors and Consultants the neonatal care we received didn't just save our sons lives, it saved our family. Thank you, I am proud to be a part of the IFDC project [Fig. 3](#).

We spent 130 days in total in hospital, we spent 13 weeks living away from home and this can destroy you. I always dreamt of our son riding down our drive on a bike and thankful for the support and love we can see a bright future ahead [Fig. 4](#).

Jenny, Alex and Jack

Our son Jack was born at 29 weeks and 5 days weighing only 3lb or 1360 g. It was a terrible shock and not something you ever plan for. At the beginning of our journey our primary focus was working with the doctors and nurses to care for Jack, and thankfully he progressed well, moving from intensive care to low dependency within the first week of his birth.

Once things were more stable we were approached by the Integrated Family Delivered Care team to take part in their programme of support. We really appreciated this sensitivity in waiting until we were able to take the lead in Jack's care [Fig. 5](#).

The programme made a huge difference to our journey, turning it from a very frightening situation to something which we could take control of. The free IFDC app provided us with vital information and allowed us to track Jack's development without relying on



Fig. 3. Finnley, Stephanie and Martin.



Fig. 4. Jenny, Alex and Jack.



Fig. 5. Alex giving Jack a bath.

Google and misinformation. The app was something we used after we left the hospital and found an enormous support. The IFDC programme taught us to care for Jack, changing, feeding, giving medication and most importantly doing skin to skin which is vital for both the baby and parent. We were given the opportunity to feel like his primary carers. This early bond was so important for us all, and being able to take control of Jack's care which included presenting him at rounds to the doctors, it felt like we were part of the team and we were all working together to bring our little boy home as quickly as possible [Fig. 6](#).

Other things which may seem small to some made a huge difference to us, providing lunches, holding parent's groups which not only provided us with information on a range of topics but allowed us to become close to other parents going through this extraordinary journey, many of whom we are still friends with. A learning journal was also provided to record all of our achievements.

We got to bring Jack home after 6 weeks of being in hospital, a lot earlier than expected and we came home confident of being able to care for our son because of this programme. We never thought we would find the journey of having a premature baby a positive one but this scheme made this possible and we are so grateful and thankful to everyone involved.

Jas, Kiran and Harlie

Harlie arrived at 26wks, 14 weeks early. She was so tiny, we were so scared. Kiran 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



Fig. 6. Jenny, Alex and Jack going home.

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 program 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 Harlie - even the staff could tell there was something different about us! Fig. 7.

Natalie and Lawrence

Our baby boy was born at 25 + 5 weeks weighing 838 g. We were completely unprepared and in shock as to what had just happened. Over the first couple of days we felt disconnected from our tiny baby boy and completely useless. We didn't feel like his parents and could not do anything to help him.

Then we met the IFDC co-ordinator. She was the first person to suggest touching him. We were taught how to touch him and how to comfort him. It was the most amazing feeling in the world Fig. 8.

Over the next couple of weeks we were introduced to the Integrated Family Delivered Care programme. Being taught how to change our baby's nappy, how to give him his milk through his NG tube and being able to have skin to skin finally made us feel included in his care. The teaching sessions that we attended encouraged us to do more and made us feel more confident when

handling him. We felt useful and were actually being his parents Fig. 9.

Having sessions where we got to talk to specialists allowed us to ask questions and have a better understanding of everything that was going on with our baby. Having all the information made us feel more in control and confident in the treatment he was receiving.

By the time we were transferred to another hospital we were doing most things for our baby. We could present him on ward rounds and knew everything that was going on with him. We were a bit anxious to be leaving Queen Charlotte's as we were unsure how involved we would be allowed to be at the next hospital. However, the letter we were given and the list of competencies we had helped us to transfer our skills to the new hospital and be able to be just as included in his care there.

We are so thankful for the care that our baby boy received at Queen Charlotte's hospital but also for the support we received while there. We were useful and involved which I believe also aided in our son's recovery and his positive relationship with us.

Sena and Mirai

My daughter was born at 24 weeks and 5 days. At the time I had no idea about the world we were about to enter. The day she was born I was too unwell to go with her to the NICU. It was not until over 12 h later that I first ventured onto the unit. It was the middle of the night, the lights were dimmed but there was still a lot of noise. I was taken to an incubator and told this was my child. I recall thinking are they sure? She was small and see-through but moving so that gave me a small level of comfort as I left her for the night, crying all the way down the corridor and down to the ward. The following morning I returned to the beeping. Little did I know then, that turning the corner that led to the ICU would trigger a stress response every time. The beeps would become associated with desaturation, or some other issue. Certain beeps still cause an autonomic response for me. Seeing the unit in the daylight was another learning experience. The machines suddenly seemed more real. Maybe I was recovering from the shock of the previous day. I knew that if I wanted to be part of this process I would need to be informed. However, with so much to take in, so many numbers, and my heightened emotional state, my mind was not processing information efficiently. The nurse looking after my daughter informed me that her gas test was good. I had no idea what he was talking about and did not ask immediately. I was focused on the numbers on the monitor. I asked what each number meant and he told me, then I asked about where the numbers should be for a healthy baby. He tried to draw my attention back to just looking at my baby. But with every sound, my eyes darted to the monitor. I wanted to ask more questions but was aware that the team were there to work and not to be distracted by a neurotic parent. Little did I know how welcomed my questions would be Fig. 10.

The first day on the unit I sat still, saying little, feeling desperately sad. The wonderful nurse kept trying to keep my spirits up, but I could barely crack a smile. However, within a few days, the nurses, doctors, consultants, pharmacist, dietician were becoming more familiar. And I grew more confident about asking questions and becoming informed. I still saw myself as an outsider looking in. At the first all team meeting, five days later, I was overwhelmed by the number of people around the incubator discussing the next course of action. Then they asked me what I thought, I didn't know. They were the experts, what could I offer to the conversation that would be useful? Over the next few weeks and months I learned that I did have something to contribute, I learned that my voice was heard and listened to. I was amazed at how these wonderfully knowledgeable people, were including me in the care for my baby. I



Fig. 7. Harlie.



Fig. 8. Leo.

was starting to feel useful. Not just an observer but now also a participant. There were several occasions when my voice was the deciding one on what to do next. It took me a long time to feel like a Mum, but this practice of inclusion facilitated and sped up that process.

After two months, my daughter was well enough to move to the special care unit. I was so proud of her. I did not realise that my involvement in her care was about to be increased. I didn't know it could increase. Instead of asking permission I was expected to take the lead. I was unprepared for that. I was unsure of myself and knew this was going to be another huge learning curve for me. However, the team were supportive. Their trust in my judgment helped me to trust my judgement too. The first time I presented my daughter on a ward round was incredibly nerve wracking. I was shaking and conscious that I might say things in the wrong order, mispronounce technical terms or make some other error. Even after rehearsing with my fantastic nurse, I was lacking confidence. The smiling and nodding faces of the team helped those nerves a little. I knew I was



Fig. 9. Natalie and Leo.



Fig. 11. Sena and Mirai.

not alone. I had my supportive nurse next to me who interjected when I looked at her for guidance. She praised my effort once it was over and that encouraged me and made me less nervous the next time around. I presented once on camera, which was exciting and anxiety provoking. However, the guidance I received made me feel up to the challenge Fig. 11.

Being an active member of the team charged with taking care of my daughter helped to solidify my identity as a Mum and prepared me for the follow-up discussions I would have with medical staff once we left the unit. I will always be indebted to all members of the team for the love I received during the 17 weeks we spent on the unit. I was with Family. I can never thank everyone at QCCH NICU enough for their approach, attitude, patience and care.



Fig. 10. Mirai.

Summary

The parent experience gives us a powerful insight into what it is like to be a parent in neonatal care. Common themes emerge; the initial admission is shocking and stressful, consistency in care and information is extremely important. Good communication and interactions are vital to ensure parental autonomy and trust and staff providing respectful, loving care makes a difference (Gallagher et al., 2017).

Skin-to-skin often appears to form the basis for the start of the IFDC process. Close proximity of mother with her baby moves her from ambivalence and creates the initial feelings of parenting and the inner need to provide her baby's care. From this initial experience parents feel useful and realise the importance of the care they can provide. They are encouraged to have regularly closeness and begin their journey of attunement to their baby leading to reciprocity, commitment and a close and loving bond with to their baby (Maastrup et al., 2017).

For IFDC to succeed in optimising neonatal outcomes for parents and their babies there is a fundamental need for staff to listen and learn from the parent experience and involve them in service planning. Health professionals have to accept, when working in shifts and in rotation, that parents empowered to be the primary caregivers through the IFDC programme are presenting the continuity and often the deepest understanding of their baby's condition and management. IFDC is a model of care by families for families.

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With grateful thanks to all our parents who have contributed to this paper, we couldn't do this without you. Reliving these experiences and generously sharing them will enable others to walk in your shoes and help us further understand the parent experience to improve our care. Thanks also to Deanna Gibbs for her work which we have drawn heavily on in structuring this article.

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