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Bliss
for babies born
premature or sick

Supporting better mental health on the NNU – for parents and staff

New research conducted by the premature and sick baby charity Bliss reveals that 80% of parents whose babies were admitted into neonatal care think that their mental health suffered after their experience, with 35% reporting that their mental health was ‘significantly worse’ after their time on the neonatal unit (NNU). Between 7 June and 2 July 2018 Bliss conducted an anonymous survey with 589 parents who had an experience of neonatal care. The survey also found that:

- 23% of respondents were diagnosed with anxiety after their neonatal experience
- 16% were diagnosed with post-traumatic stress disorder (PTSD) after their time on the NNU
- 14% were diagnosed with postnatal depression
- 39% felt they had developed a mental health condition after their experience although they were not officially diagnosed.

The survey further revealed a lack of support for new parents, with 62% of respondents reporting they had no access to formal psychological support (eg counselling or talking therapies) when they needed it while their baby was on the NNU. Only 8% of parents surveyed felt they received the right amount of support while on the NNU and 45% of parents said they had no access to much-needed psychological support after leaving the unit.

What support is there for parents on the unit?

National standards for neonatal care across the UK indicate that all parents on NNUs should have access to psychological and social support, including a trained counsellor.¹ However, Bliss’ past research shows that no country in the UK is

England²

41% of NNUs said that parents had no access to a trained mental health worker.

30% of NNUs said parents had no psychological support at all.

Wales³

45% of NNUs are not able to offer parents access to psychological support of any kind.

None of Wales’ three NICUs have a dedicated trained mental health worker.

Scotland⁴

12 out of 13 units have access to some kind of trained mental health professional, however access is often inadequate to meet demand.

Northern Ireland⁵

Five out of seven NNUs do not have dedicated access to a mental health professional.

The only NICU in Northern Ireland does not offer any access to a mental health professional.

TABLE 1 Neonatal units in the UK are not reaching the national standards for psychological support.

reaching the national standards for psychological support in NNUs (TABLE 1).

What is Bliss doing about mental health?

Bliss’ research demonstrates the vital need for better mental health support for parents while their baby is on the NNU and beyond. Caroline Lee-Davey, Chief Executive of Bliss, says: “At present, none of the UK nations are reaching the national standard for providing psychological support to parents on units and our research demonstrates how detrimental this can be to parents’ health and wellbeing. Bliss calls for every UK government to ensure that mental health support is available to each parent who has a baby in neonatal care.

“Bliss is working hard to ensure parents receive the help they need while on the NNU and beyond. We are currently producing new information and a podcast for parents about mental health that will be available later this year. In the meantime, we continue to recruit and train volunteers who provide direct support to parents with babies in NNUs across the country.”

How can neonatal professionals support parents on the unit?

With a lack of specialist support in place, Helen Aitchison, psychotherapist at Barts Health NHS

Bliss surveyed parents about their experiences of mental health support during neonatal care.



Trust, believes that it is vital that healthcare professionals on a neonatal unit familiarise themselves with the symptoms of perinatal mental health problems.

Helen says: “Being able to recognise the symptoms of perinatal mental health problems can help staff tell the difference between normal psychological reactions that may require a ‘watch and wait’ approach and more long-term or severe conditions that indicate referral for psychological assessment and treatment. Information about mental health during the perinatal period can be found on the Tommy’s⁶ and Best Beginnings⁷ websites. Staff could also consider attending a relevant learning activity (continuing professional development) to deepen knowledge.

“When meeting or speaking with parents on the unit, remember to be kind and compassionate. Having a sick or premature baby is a traumatic experience and it is likely that they will be feeling overwhelmed; your reassurance and understanding will be appreciated. Being by a cot side can be a frightening and lonely experience, whenever time permits try to sit and spend some time talking to and building a relationship with them. Encourage the parent to practise self-care when they are away from the hospital by doing things they enjoy and seeing friends and family members.

“If you think someone is struggling, discuss with the multidisciplinary team so that a support plan can be put in place while the baby is on the unit. If appropriate, liaise with other professionals involved in their care (eg social worker, midwife, counsellor) in order to create a support network around the family. Discuss referral to their GP or local perinatal mental health services if you think that they need more specialist input.”

What are the warning signs?

Helen recommends that health professionals should listen carefully to parents – they may be subtly telling you they are struggling with their mental health but not want to tell you explicitly for fear of being judged a ‘bad parent’. Don’t necessarily take ‘I’m fine’ at face value – it’s always worth exploring a bit more.

Check if they are caring for themselves. Do they look well or tired, thin or unkempt? As health professionals you have experience in observing and being with people – what are you seeing, what do you feel?

Find out about any mental health history, what treatment they had (if any) and how they coped. Past mental health problems increase the risk of someone becoming unwell in the perinatal period, so it’s important to check this out. Although uncommon (around 1 in 1,000 births), postpartum psychosis is a severe mental health condition that usually occurs in the first few weeks after giving birth and requires immediate psychiatric assessment and treatment. Learn about symptoms including hallucinations, delusions and mania and always refer for assessment if you have any concerns.

Notice how often they are visiting. If rarely, then explore why this is the case. It may be that it is a long way to travel or they have other childcare commitments, however it might also mean that they are avoiding coming in due to anxiety or the trauma of the experience. Conversely, if parents are there all the time, check if they are looking after themselves, getting some rest or whether this is a sign of excessive anxiety about leaving their baby.

Case studies

Katie, Jonathan and Ray

Katie and Jonathan Jones’ son Ray was delivered by emergency caesarean section at 27 weeks’ gestation in 2017. Katie said: “Our world turned upside down from the moment Ray was delivered. During his three month stay in hospital we felt emotionally and physically drained. I’d wake up hallucinating and would hear the sound of alarms in the shower. From my experience I don’t feel there is enough support for the parents of premature or sick babies while their baby is in hospital. The only people we could talk to were the nurses looking after our baby.

“I don’t think I’ll ever get over what happened on the neonatal unit. We have seen things that no parent should see and as much as they try and shield you from what’s happening on the ward around you, it’s not always possible. I now have anxiety. I am emotionally scarred and so is my husband. I look at Ray and think how incredibly lucky we are but I can never get over what we went through.”



Katie and Jonathan Jones with their son Ray.

Alice and her daughter Isabelle

Alice Clements gave birth to her daughter Isabelle at 33 weeks’ gestation in 2014. Alice said: “Isabelle was in hospital for four weeks. I spent 10-12 hours a day sat next to Isabelle’s incubator alone. Some days I didn’t talk to anyone but the nurses and after Isabelle came home I sank into a deep depression.

“When Isabelle was six months old, I received six sessions of free counselling, which was a lifeline. I couldn’t afford to keep going after the six sessions were over so my recovery was put on hold. When I returned to work I developed severe anxiety and had at least two or three panic attacks a day. I started to have flashbacks of my pre-eclampsia, delivery and the neonatal unit, and was finally diagnosed with post-traumatic stress disorder.

“In July 2016, I saw another counsellor for weekly sessions lasting 13 months. I built myself back up right from the ground and eventually felt ready to have another baby. In December 2017 I had my son and now my family and I are stronger than ever.”



Isabelle in the NICU.

Be aware of any changes in parents' mood, behaviour and interactions during the course of their time on the unit. Some parents' reactions to the trauma of birth are normal and will abate over time, however if they appear to remain low in mood or anxious over a longer period, this may indicate a more chronic problem such as postnatal depression or postpartum PTSD.

If you have worries, speak to colleagues and discuss in the multidisciplinary team meeting; have others observed and/or felt concerned?

Take care of your own mental health

Working in neonatal care can impact on your own mental health. Here are some of Helen's tips for taking care of yourself on the NNU:

- accept that this intense work with traumatised families will have an impact – you can't 'walk in the rain without getting wet'
- learn about the psychological and physical signs of burn-out and secondary traumatic stress and stay alert for them
- develop a support network, both professional and personal
- attend supervision, debriefing sessions, reflective practice, Balint groups, Schwartz Rounds, etc
- seek out further support from a counsellor, psychotherapist or occupational health if needed
- always go for breaks, lunch and take annual leave
- take time off if you are unwell and ask to be signed off if needed
- balance work life with other activities and interests
- be kind to yourself.

Conclusions

It is clear from Bliss' latest research that far more needs to be done to support the mental health of parents whose baby requires specialist care. It is not a burden that unit staff should take on alone, especially when they are so overstretched and understaffed.

Bliss will continue to call on governments to ensure that mental health support is available to each parent who has a baby in neonatal care across the UK. To lend your support you can join our campaign network at: <https://bit.ly/2n6ZO40>.

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