Bliss Statement: COVID-19 and parental involvement on neonatal units

Wednesday 8 April 2020

Information correct as at time of writing; this document will be updated regularly in line with new and emerging guidance and evidence.

Bliss is the UK's leading charity for babies born premature or sick. Every year over 100,000 babies across the UK will be admitted to neonatal care after they are born - many will need to receive life-saving care for weeks or months before they are ready for home. Sadly, some babies will never go home at all.

In response to the growing intensity of the COVID-19 pandemic, hospitals across the UK have severely limited who is able to come onto hospital sites in an attempt to reduce the spread of infections. This will help protect vulnerable patients, and the dedicated staff who care for them, from contracting the virus. These restrictions have also affected parents' access to their babies in neonatal care.

Bliss fully recognises the need for these additional restrictions as part of the national response to reduce COVID-19 infection risk overall, as well as specifically to reduce the risk of infection for babies born premature or sick and neonatal staff. This sits alongside other measures to protect NHS patients and staff including further COVID-19 testing and significantly increased use of personal protective equipment for NHS staff.

Neonatal units across the UK strive to care for babies in a family-centred environment, where parents are partners in delivering their baby's care. At Bliss we know that, even with these restrictions in place, it will be possible for neonatal units to continue an approach which facilitates parental involvement in their baby's care. We know this is best for babies and best for parents; and that neonatal health professionals will want to continue to do this in a way that is safe for babies and safe for their staff.

Bliss is keen to ensure that this approach is prioritised and delivered consistently across the UK, in recognition of the significant impact that parental involvement in their baby's neonatal care has on both their immediate and long-term outcomes, and in order to provide clear and consistent messaging to all the parents whose baby is in neonatal care now or may be admitted in the coming weeks and months.

We therefore set out below:

- Current guidance for parental access to neonatal units
- Current guidance for parental involvement in their baby's neonatal care
- Bliss' position on parental access and involvement throughout the period of COVID-19 pandemic restrictions
- Bliss' recommendations for parental access to and involvement in neonatal care.

Current guidance for parental access to neonatal units

Guidelines issued by health services across the UK[1] have mandated that most hospital departments should not allow any visitors at all. An exception to this is for parents if their baby or child is in hospital. In this instance, guidance states that only one parent should be with their child at any one time.

The British Association of Perinatal Medicine (BAPM) and the Royal College of Paediatrics and Child Health (RCPCH) have developed specific guidance for neonatal settings and state that only parents should be permitted onto units, with no other wider family - including siblings - permitted at this time.[2] As part of measures to protect capacity, and to maintain safe staffing levels, units should upscale 'all measures aimed at early discharge'.[3]

Mothers who are suspected or confirmed to have COVID-19 should not be allowed onto the unit until they have tested negative or until 7 days after the onset of their symptoms and they are symptom-free. If the baby's father, or mother's partner, has no symptoms they will need to self-isolate for 14 days.[4] This is in line with current Public Health England Self-Isolation Guidance.[5]

Like all other departments, neonatal services are part of a whole system approach to combat COVID-19 and resources are being shifted to ensure the NHS is able to cope with increased demands in certain areas of the health service. This means community outreach staff are likely to be redeployed temporarily to different settings.[6] Additionally, neonatal units are likely to be under increased staffing pressure as nurses and doctors have to self-isolate if they, or someone in their household, show symptoms. Implementing a testing regime for healthcare professionals has been slow, and the impact large – one report from the Royal College of Physicians suggested a quarter of medics are currently absent across health services.[7]

[1] Restrictions on visitors has been introduced across the UK: England, Scotland, Wales and Northern Ireland

[2] Royal College of Paediatrics and Child Health and the British Associal of Perinatal Medicine (2020) COVID19 – Guidance for Paediatric Settings: Working in neonatal settings accessed online at: https://www.rcpch.ac.uk/resources/covid-19-guidance-paediatric-services#working-in-neonatal-settings

[3] RCPCH & BAPM (2020) COVID19 –Guidance for Paediatric settings accessed online at: https://www.rcpch.ac.uk/resources/covid-19-guidance-paediatric-services#working-in-neonatal-settings

[4] BAPM (2020) COVID-19 pandemic: Frequently Asked Questions within Neonatal Services A BAPM supplement to RCPCH guidance (currently unpublished)

[5] Public Health England (2020) Stay at home: guidance for households with possible coronavirus (COVID-19) infection, accessed online at: https://www.gov.uk/government/publications/covid-19-stay-at-home-guidance/stay-at-home-guidance-for-households-with-possible-coronavirus-covid-19-infection

[6] NHS England and NHS Improvement sent a letter to all Trusts on 17 March 2020 making a host of suggestions for service change. Among these was the redeployment of community based staff to different roles. A copy of the letter can be accessed here: https://www.hsj.co.uk/download?ac=3044892

[7] Royal College of Physicians (2020) COVID-19 and its impact on the NHS Workforce accessed online at: https://www.rcplondon.ac.uk/news/covid-19-and-its-impact-nhs-workforce

This guidance is being kept under review and will likely be regularly updated over the coming weeks and months. It is also hoped that increased testing will help to address current challenges relating to staff absences.

Current guidance for parental involvement in their baby's neonatal care

BAPM endorses the continuation of parental involvement in their baby's care throughout the COVID-19 pandemic, affirming that parents remain partners in care-giving for their baby. Their guidance also notes that parental involvement in the delivery of basic tasks and their baby's care may prove beneficial to units as staffing pressures become increasingly acute.[8]

Guidance for the provision of Kangaroo (skin to skin) Care notes that there is no evidence that it is unsafe for COVID-19 negative parents to engage in skin-to-skin contact with their baby, as long as safety protocols are followed. Kangaroo Care should therefore continue to be encouraged and facilitated for all babies where it is safe to do so, as per usual practice.[9]

Bliss' position on parental access and involvement throughout the COVID-19 pandemic

Ensuring the safety of vulnerable babies on neonatal units during the COVID-19 outbreak is paramount. But parents are not visitors, and they need to continue to be partners in delivering their baby's care and decision making.

We know that the current guidelines which restrict parent and wider family access are extremely difficult for both the families of premature and sick babies, and the staff who have to implement them, but they are necessary in light of these unprecedented circumstances.

However, we are aware this guidance is being implemented in a variety of different ways. For example, Bliss is aware of policies where only one nominated parent is allowed onto the unit; policies where only mothers are allowed onto the unit; and, increasingly, policies which restrict access to a matter of hours (typically a maximum of two) - or even less. As a result, some parents - usually fathers and partners - are unable to spend time with or be involved in their baby's care at all.

There is currently **no guidance or evidence** to suggest that restricting contact time is necessary. Indeed, BAPM guidance on Family-Integrated Care and COVID-19 states that neonatal services should "negotiate a policy where at least one parent can be present for as long as possible within current constraints".[10]

[8] BAPM and Bliss (2020) Family Integrated Care for COVID-19 – Frequently Asked Questions accessed online at: https://hubble-live-assets.s3.amazonaws.com/bapm/redactor2_assets/files/422/FAQs_-_FIC_Covid19_-_version_2.docx.pdf

[9] Kangaroo Care Day (2020) Kangaroo Care / Skin to Skin Contact in Neonatal and Pediatric Intensive Care Units During COVID-19 accessed online at: https://kangaroo.care/blogs/covid-19/guidelines

[10] BAPM and Bliss (2020) Family Integrated Care for COVID-19

Careful consideration must be given to the potential impact of disproportionately restrictive parental access policies on families of the most critically ill babies - and how these may affect parents' ability to be at the unit at all during their baby's final hours - and steps taken to mitigate against this scenario occurring.

Every parent wants what is best for their baby, and will comply with restrictions, no matter how difficult, if that means their baby will be safe - but **any limitations on access and involvement must be proportionate and based on evidence.** Great strides have been made by neonatal units in recent years to ensure care provided is family-centred, including through implementation of the Bliss Baby Charter[11]. This pandemic will be temporary, but the impact on families with babies receiving neonatal care during this tumultuous period will be enduring.

Neonatal services must commit to returning to usual standards of family support and involvement as soon as possible.

Why is parental involvement in neonatal care important?

Improved outcomes of babies

It is well established that parental involvement in their baby's neonatal care enables babies to have the best developmental outcomes - including increased weight gain and improved breastfeeding rates.[12] Equally, parents who are supported to be with their baby for prolonged periods of time and to be partners in delivering their baby's care report increased parental confidence, reduced stress and anxiety scores - all of which will be beneficial for their baby[13].

BAPM guidance affirms that parents are partners in delivering their baby's care, and that their continued involvement in care provision may be beneficial to neonatal units during the crisis. For parents who are appropriately trained and supported, undertaking tasks such as mouthcare, changing nappies, comfort holding and giving oral medications can enable clinical staff to focus on specialist tasks, which will be particularly beneficial as neonatal units become short-staffed during the pandemic - exacerbating existing staffing gaps across the service.[14] [15] In addition, enabling parents to provide a significant proportion of hands-on care will reduce the number of clinical team members who need to directly handle each baby, reducing the infection risk to babies from clinical staff.

[11] Bliss (2015) Bliss Baby Charter Audit Toolkit
[12] O'Brien et al. (2018) Effectiveness of Family Integrated Care in neonatal intensive care units on infant and parent outcomes: a multicentre, multinational, cluster-randomised controlled trial, Lancet Child and Adolescent Health VOLUME 2, ISSUE 4, P245-254, APRIL 01, 2018
[13] O'Brien et al. (2018) Effectiveness of Family Integrated Care in neonatal intensive care units
[14]BAPM and Bliss (2020) Family Integrated Care for COVID-19
[15] O'Mara et al. (2020), Neonatal nursing workforce survey – What does the landscape look like in England? Journal neonatal nursing Vol.26

Reducing the impact on families

A neonatal experience is extremely stressful and often traumatic. Bliss' research has shown 80% of parents felt their mental health was negatively impacted by their experience[16]. In addition, there is a raft of academic evidence which shows the association between a neonatal experience and detrimental impact on the mental health of both parents[17] [18].

Parental involvement in their baby's neonatal care is also critical for preventing difficulties after discharge home. With many community outreach services temporarily suspended, and families facing lockdown at home after their time on a neonatal unit, it's more important than ever that parents leave the unit confident and well bonded with their baby. Ensuring opportunities for parental involvement will be crucial to achieving this – particularly at a time when neonatal units will be working to ensure babies can be discharged home as early and safely as possible.

Units should consider the impact of imposing policies which only allow the same parent to attend the unit, or severely restrict the hours parents are able to be with their baby. Many families will live a significant distance from the neonatal unit where their baby is being cared for. Many family lives are being complicated due to current lockdown restrictions – including social distancing and self-isolation measures for vulnerable people - making it harder for parents to be on the neonatal unit already. Additionally, many family lives are being complicated by job insecurity and a potential loss of income – putting additional strain on them, at a time when their neonatal experience is also adding additional, unexpected costs. Bliss research has previously shown parents spend around £282 every week their baby is in neonatal care on top of normal household costs due to additional travel and parking, food and drink, childcare and accommodation.[19] Restricted access, which is disproportionate and not introduced on the basis of clear evidence, may result in some parents being unable to be with their baby throughout their neonatal stay.

Parental involvement and presence during palliative and end of life care

For some babies, their neonatal journey will not end with discharge home. A baby dying in neonatal care is always tragic, and while nothing will ever lessen the pain for families, the provision of excellent bereavement care which enables parental involvement in decision making and opportunities for memory making can have a lasting positive impact.

Neonatal services should ensure that both parents are able to be with their baby during palliative and end of life care and, where it can be accommodated, wider family members such as siblings should be able to be present too.

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[16] Bliss (2018) Bliss releases new research on mental health, accessed online at: https://www.bliss.org.uk/news/bliss-releases-new-research-on-mental-health

[17] Vigod, S.N., Villegas, L., Dennis, C.L., Ross, L.E. (2010) Prevalence and risk factors for postpartum depression among women with preterm and low-birth weight infants: a systematic review, BJOG, 117(5), pp.540-50

[18] Noergaard et al.,(2017).

[19] Bliss (2014) It's not a game: the very real costs of having a baby in neonatal care

Recommendations

Bliss asks neonatal services to commit to re-establishing usual levels of family support and involvement as soon as possible when the pressures caused by COVID-19 ease. Until that time comes, services should seek to maximise opportunities for parental access and involvement.

Parental access

- Negotiate parental access policies which allow unrestricted access for at least one parent at a time. **The hours a parent can be with their baby should not be restricted routinely.**
- Both parents should be supported to be involved in their baby's care. **Avoid parental access policies which call for a nominated parent only or mothers only**.
- **Ask parents to comply with infection control rules in line with those followed by healthcare professionals** in order to minimise infection risk, rather than excluding them from care.
- **Enable parents who are unable to be on the unit to have video link access to their baby**. Ensure parents are contacted and able to be involved, as much as possible, in care decisions related to their baby.
- **During end of life care both parents should be able to be present and involved in decision making, care and memory making.** Where possible within current constraints, wider family members (such as siblings) should also be involved.
- **Ensure consistency between access policies at Network Level** to minimise disruption to families who experience transfer between hospitals.

Parental involvement:

- Where possible, **parents should be the only people who touch their baby**. Ensuring parents are able to carry out cares and basic tasks reduces the risk of infection transmission from healthcare professionals on the unit to babies.
- **Maintain high standards of bereavement care, in line with the National Bereavement Care pathway and other locally agreed best practice guidelines.**
- Where possible **provide additional financial and practical support to enable as many parents to be with their baby as possible.** For example, allow parents access to meals from the meal trolley if leaving the unit for food will mean they are not allowed back onto the unit that day - an increasingly likely scenario given most hospital food outlets have been shut due to COVID-19 restrictions.
- Explore options to allow **parents reliant on public transport to be reimbursed for taxi use** to limit their exposure to COVID-19 and allow **parents who drive to the unit access to free car parking, where this is not in place already.**
- Where there are existing measures in place to support parents with costs associated with a neonatal stay, such as the Neonatal Expenses Fund in Scotland and locally agreed guidelines, **ensure parents are signposted to this regularly from admission and claim forms and leaflets are easily accessible.**
- **Signpost parents to external organisations, such as Bliss,** for further practical and emotional support.