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

Updated 7 January 2021

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.

Updates 7 January 2021

- Updated to reflect new lockdown measures imposed in January 2021
- Current guidance section updated to reflect current national guidance across the UK
- New evidence included demonstrating the impact of parent access restrictions to babies and their families

New substantive additions to this version have been written in teal throughout the document.

In response to the growing intensity of the COVID-19 pandemic, hospitals across the UK severely limited who was able to come onto hospital sites to reduce the spread of infections. These policies were introduced to protect vulnerable patients, and the dedicated staff who care for them, from contracting the virus. While many units had started to amend their policies to ensure both parents could be present and be involved in their baby's care, and some units have even been able to return to full unrestricted access for parents, these restrictions continued to affect parents' access to their babies, and their ability to deliver their baby's care.

Hospitals across the UK are once again adapting their policies to cope with the strain which is being put on the system to ensure everyone in hospital is kept safe, and we anticipate some services will introduce more restrictive measures which may limit parent access and involvement on neonatal units during this time. However, it is critical that any restrictions to access are proportionate, kept under regular review, and still ensure both parents are supported to be present and involved in their baby's care. Services should also actively seek to maximise their testing capacity and prioritise parents of babies in neonatal care for rapid testing to ensure parent access remains as close to unrestricted as possible over the difficult weeks ahead.

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:

- **NHS England**[36] issued new guidance on 14 December 2020 which is aligned with guidance from the Royal College of Paediatrics and Child Health (RCPCH) and the British Association of Perinatal Medicine (BAPM) and states ''parents are partners in care and should not be considered visitors.'' NHS Trusts are required to ''maximise opportunities for parents to be with their babies and to identify how to facilitate parental presence at all times of day''. The guidance requires Trusts to work creatively to ensure parental access is supported as fully as possible, and to ensure plans are in place to support parents who test positive for COVID-19, including through using video technology. NHS England expects Trusts to 'urgently' take action to ensure parents are able to be with their baby in neonatal care, as well as ensuring women can be accompanied by a partner throughout the maternity pathway. Increased access will be achieved by following three steps:
    - Undertaking risk assessment to identify where there is an elevated risk of transmission
    - Addressing issues identified in the risk assessment by making changes to the configuration of available space and ensuring appropriate infection prevention and control measures are in place.
    - Using available testing capacity to increase access. In neonatal services specifically, NHS England sets out that routine testing of parents should be put in place to enable maximum access when negative test results are received.
- The **Scottish Government** [37] is clear that both parents or care givers should be supported to have maximum access to their baby across all protection levels, and both parents should be supported

to be present if their baby is critically ill or receiving end of life care. The guidance also states that parents should be offered opportunities to care for their baby without wearing facemasks to support bonding and skin-to-skin care. Physical distancing should be maintained, and risk assessments should be undertaken which also assess the impact on babies and their families if access restrictions are implemented.

- The **Northern Ireland**[38] Department of Health sets out that two parents or caregivers should be supported to have access to their baby in neonatal settings. Whether access can be facilitated for both parents at the same time is dependent on the Surge Level. When the Surge Level is 'High' or 'Medium' only one parent is able to attend at a time. If a baby is critically ill or receiving end of life care other family members or caregivers may also be granted access.
- **Wales Government**[39] currently advises that only one parent or carer can be present at a time.

In addition, BAPM and the 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]

BAPM guidance states that ''it is essential that the mother and her partner are ***never*** considered to be visitors within the neonatal unit – they are partners in their baby's care and their presence should be encouraged and facilitated as much as possible.'' Additionally, the guidance encourages services to reflect how best to maximise involvement and facilitate parental presence at all times – including during ward rounds - while maintaining social distancing, and sets out that parents should be supported to be involved and present during end of life care, even if COVID-19 positive.[23]

Mothers who are suspected or confirmed to have COVID-19 will not be able to go 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] BAPM recommends that units should offer the same testing protocols to symptomatic parents and testing of suspected contacts as are applied to staff, in order to minimise unnecessary separation.[24]

This guidance is being kept under review and will likely be regularly updated over the coming weeks and months.

Current guidance for neonatal transfers

The Neonatal Transport Group (NTG) has also stated that parents are currently unable to travel with their baby during transfer, except in exceptional circumstances, for example when the baby is being transferred for palliative care, or is not expected to survive.[19]

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. As set out above, they have affirmed that parents remain partners in care-giving for their baby and 'their presence should be encouraged as much as possible'. The guidance also stresses the importance of parents being present together, unless this is clearly detrimental to other babies or staff, and that mothers and their babies should be considered 'the same biological entity'. 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.[7]

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.[8]

Since 15 June 2020 it has been compulsory for hospital visitors in England to wear face coverings[28]. However, following concerns raised by Bliss and neonatal professionals, RCPCH guidance has been updated to reiterate that parents are not visitors, and suggests a more nuanced approach can be taken in a neonatal setting. They set out: ''*The risk…must be balanced with potential harm to parent-infant relationships and infant development if parents' faces are always covered in the neonatal setting. For example, given that parents and their baby form one family "bubble", it seems unlikely that parents wearing face coverings at the cot side offers significant additional protection to their baby if they are sufficiently spaced from other parents/visitors and staff.''*[29]

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.

However, guidance has been implemented in a variety of different ways. For example, Bliss is aware of policies where only one nominated parent is able to go onto the unit; policies where only mothers are able to go 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.

Bliss understands that local challenges arising as a result of COVID-19 are likely to change over time. **Parental access policies should be kept under regular review to ensure parents have as much access to their baby, and the opportunity to be involved in their baby's care, as possible in response to changing**

local need. In line with BAPM guidance, units should be working to facilitate unrestricted parental access – including the opportunity for both parents to be present for at least part of the day.

Additionally, Bliss and Twins Trust are aware of parents of twins, triplets and more who, in units imposing time restrictions, are being asked to divide the length of a single time slot between all their babies. We are also aware of parents being asked that they choose one baby to provide care to during that particular visit, and to alternate between babies on different days. **It is vital that parents have an equal amount of time to spend with each of their babies every time they come to the neonatal unit, and the time spent with each baby should not be restricted routinely.** Parents must have the opportunity for bonding, to provide skin-to-skin care, and time to speak with staff on the unit regarding each of their babies individually.[i]

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''.[9]

Careful consideration must be given to the potential impact of disproportionately restrictive parental access policies on families of the most critically ill babies. For the sickest babies, neonatal care can be unpredictable, and a baby's condition can deteriorate quickly. Consideration must be given to how restricted access may affect parents' ability to be on the unit at all during their baby's final hours, and steps should be taken to mitigate against this scenario occurring.

Evidence suggests there may be a detrimental impact on babies' development and bonding if their parents are required to wear face coverings continually. Bliss has heard from concerned neonatal professionals about the impact of this blanket hospital policy in England and are aware that some units are implementing a more flexible approach – for example, encouraging parents to remove their face coverings when they are cotside with their baby, and doing skin-to-skin, while still requiring them to wear face coverings when speaking with staff or moving around the unit / hospital site. **In line with RCPCH and BAPM guidance, Trusts should consider the impact that wearing a face covering may have on babies' bonding and development, and should support neonatal units to allow parents to care for their baby at the cot-side without wearing a face covering if they are not in conversation with or being supported by staff.**

Where Trusts or Health Boards feel it is not possible to safely accommodate parents removing their face coverings, or where implementing such a policy would necessitate a reduction in parental access, **Trusts should have a robust plan in place to mitigate against any potential impact by continuing to prioritise maximising parental access and actively supporting parents to provide developmentally supportive care which supports the other senses (audio, touch, taste and smell) to encourage bonding and support development.**

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[i] Position on best practice for access and involvement for parents of twins, triplets or more was kindly developed by Twins Trust, and endorsed by Bliss. For more information on how to support parents of twins and multiples throughout their neonatal stay, please visit the Twins Trust website: https://twinstrust.org/

It is also important to note that wearing a face covering or mask inhibits communication for parents and staff who are hearing impaired.[30] Good, clear communication is vital for parents to understand their baby, and to ensure they are fully able to deliver their baby's care. Enabling clear communication is also important for ensuring good staff and parent relations, particularly during a time when guidance and procedure is still changing regularly. **Services should take steps to mitigate this to ensure all parents and staff are able to communicate with one another clearly and equitably.**

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.** In line with the most recent BAPM guidelines, the same testing protocols which apply to staff should also apply to parents in order to minimise unnecessary separation. This should include testing parents displaying COVID-19 symptoms and their household.

Neonatal services must commit to returning to usual standards of family support and involvement as soon as possible. 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.[10] This pandemic will be temporary, but the impact on families with babies receiving neonatal care during this tumultuous period will be enduring.

<u>Why is parental involvement in neonatal care important?</u>

Improved outcomes of babies

Parental involvement in their baby's care is proven to be best for babies' developmental outcomes. Evidence has shown that long periods of direct care lead to increased weight-gain and improved breastfeeding rates, and skin-to-skin care has been linked to better infant reflexes at term and better gross motor development at 4-5 years. [11] [20] Further, parental involvement in care is critical for bonding and forming secure attachment. Parents who are supported to be with their baby for prolonged periods of time report increased parental confidence, reduced stress and anxiety scores.[12] Providing direct, hands on care allows parents to *feel* like parents - which may be key for their own perceptions of attachment to their baby - and physical and emotional closeness is crucial for forming strong parent-infant bonds.[21] [22]

While video technology is a vital tool to minimise the impact of separation during the pandemic, and Bliss welcomes its rapid, widespread adoption, it is not a replacement for parental involvement. For babies to experience these long term developmental benefits ongoing parental involvement must be facilitated.

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.[13] [14] 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.

Face-to-face visual engagement is important for babies' developmental outcomes, with research establishing that 'visual experience is critical for the typical development of face processing.'[31] Evidence also clearly demonstrates that babies respond preferentially towards faces or face-like configurations and appear to show a preference for their mother's face within hours of birth.[32] [33] Longer term, audiovisual speech information – i.e. watching people's mouths move while they are talking - is important for early language development. Babies born preterm may already be more likely to experience speech and language delay, and recent research suggests repeated negative experiences such as pain and exposure to noise may lead to 'atypical auditory speech processing', highlighting the importance of a developmental and family-centered approach to their neonatal care.[34]

Additionally, enabling parents and babies to look at one another is important for bonding and attachment. Research has demonstrated how physical closeness supports parents to feel emotionally close to their baby, noting that ''for many parents these feelings started when seeing their infant…parents emphasized the importance of being face-to-face and having eye contact.''[35]

Reducing the impact on families

A neonatal experience is extremely stressful and often traumatic, and emerging evidence demonstrates that restrictions in place due to COVID-19 are having a significant negative impact on families. Bliss' own research has shown 90% of parents surveyed have felt more isolated, and 70% feel their mental health has been negatively affected, by experiencing neonatal care during COVID-19. Additionally, one in seven parents surveyed reported their baby's neonatal unit had implemented a 'nominated parent' policy meaning one parent was excluded entirely from care.[40] Similar findings have also been highlighted in a *British Medical Journal Study* which also found mild to severe impacts on breastfeeding for 36% of respondents.[41]

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. They should also specifically consider the impact of these policies on parents of twins and multiples, and the disparity this may cause in parental experience within the neonatal unit.

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. [18] 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 if their baby is critically ill or during palliative and end of life care, adhering to the BAPM recommendation that ''everything possible should be done to achieve parental presence and participation in care, even for COVID-19 positive parents.'' Additionally, Bliss believes that, where it can be accommodated, wider family members such as siblings should be able to be present too.

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

- Neonatal units should facilitate parental presence at all times of day, including during ward rounds. **The hours a parent can be with their baby should not be restricted routinely**, **including for parents of twins and multiples**
- Both parents should be supported to be involved in their baby's care, and units should seek to allow parents to be present together. **Avoid parental access policies which call for a nominated parent only or mothers only**.
- **Parents of twins and multiples should have equal access to their babies**, and should be supported to spend time with each of their babies every time they are present on the unit.
- **Parental access policies should be kept under regular review** to ensure they are allowing as much flexibility as is possible to be accommodated within the local health context.
- **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.

- **In line with BAPM guidance, units should offer the same testing protocols to parents as are applied to staff, including testing of symptomatic parents and their household contacts** to minimise unnecessary separation.
- **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, including those who are COVID-19 positive, 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 or babies**. Ensuring parents can carry out cares and basic tasks reduces the risk of infection transmission from healthcare professionals on the unit to babies.
- **Parents should be supported to provide cot-side care to their baby or babies – including during skin-to-skin or kangaroo care - without a face covering, to support their babies' development and bonding.**
- **Wearing a face covering or mask inhibits communication for parents and staff who are hearing impaired.** Services should take steps to mitigate and remove communication barriers.
- **Trusts which cannot accommodate a relaxation of the face covering policy, for safety reasons or because it would necessitate the reduction of parental presence, should have a robust plan in place to mitigate against any potential impact by actively supporting parents to provide developmentally supportive care which supports the other senses (audio, touch, taste and smell) to encourage bonding and support development.**
- **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 able to go 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.

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[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] 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

[8] 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

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

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[15] 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

[16] 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

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

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

[19] The Neonatal Transport Group (2020) NTG Position Statement 24 April 2020, accessed online here: https://hubble-live-assets.s3.amazonaws.com/bapm/redactor2_assets/files/507/NTG_position_statement_24__April_2020_v3.pdf

[20] Pineda et al (2017) Parent participation in the neonatal intensive care unit: Predictors and relationships to neurobehavior and developmental outcomes, Early Human Development, 117:32-38.

[21] Treherne et al (2017) Parents' Perspectives of Closeness and Separation With Their Preterm Infants in the NICU, Journal of Obstetric, Gynecological and Neonatal Nursing, 46(5):737-747;

[22] Flacking et al (2012) Closeness and Separation in neonatal intensive care, Acta Paediatr, 101(10): 1032–1037

[23] BAPM (2020) COVID-19 Pandemic Frequently Asked Questions within Neonatal Services: A BAPM supplement to RCPCH guidance updated 6th May 2020

[24] BAPM (2020) COVID-19 Pandemic Frequently Asked Questions within Neonatal Services

[25] RCPCH (2020) COVID-19 Guidance for Neonatal Settings accessed online at: https://www.rcpch.ac.uk/resources/covid-19-guidance-neonatal-settings
[26] BAPM (2020) COVID-19 Pandemic Frequently Asked Questions within Neonatal Services
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