Baby Loss Awareness Week
9-15 October
babyloss-awareness.org

Briefing from the Baby Loss Awareness Alliance for the debate on the effect of the covid-19 outbreak on people experiencing baby loss

1.30-3.00pm, Thursday 5 November, Westminster Hall

Introduction

Thousands of parents experience pregnancy or baby loss every year. It is estimated, that in the UK:

- one in four pregnancies end in miscarriage
- one in eighty pregnancies are ectopic
- 5,000 wanted pregnancies a year are terminated for medical reasons
- 14 babies a day are stillborn or die shortly after birth, and
- 200 babies a year die from Sudden Infant Death Syndrome.

The Baby Loss Awareness Alliance and All Party Parliamentary Group on Baby Loss have been gathering evidence from organisations across the baby loss sector about the impact of the pandemic on those they represent and support. This includes women and partners who have experienced pregnancy or baby loss at any stage during the pandemic, those pregnant following loss and professionals working to support them.

The evidence is stark; while many health care professionals have worked incredibly hard to provide good care for women and their partners, COVID-19 has exacerbated existing challenges, and has overall had a negative impact on them at the worst possible time of their lives.

It is essential that lessons are learnt following the first wave, so that negative, unintended consequences can be avoided in a second wave.

The impact

Involvement of partners

Partners have been excluded from appointments and scans, often not even able to join the consultation by video or speakerphone. This has led to women receiving bad news or having to make difficult decisions alone. This has been the number one issue identified by both parents and professionals on the impact on COVID-19[1]. This is particularly challenging for women who are pregnant following a previous loss and their partners. It is very concerning that despite recent guidance from NHS England on allowing partners to access pregnancy and maternity services, the vast majority of trusts are still not doing this[2].

In a neonatal setting, parental access for both mothers and partners has been severely restricted and in some case has led to parents being unable to see their baby for a significant length of time. These factors all increase the sense of isolation experienced by bereaved women and their families and limits the opportunity for parents to make memories and bond with their baby on the neonatal unit. While steps have been taken recently at a national level to ensure that partners are able to attend maternity services, and parents have greater access to their babies in Neonatal Units, there is still much work to be done to ensure this is implemented across the UK. The Scottish Government states that both parents do have access to these services in all Health Boards, but in England the picture is much more variable with recent reports of some services, which had begun to allow access for partners, re-imposing restrictions as COVID-19 infections rise.

[1] In response to surveys of women and families by Sands (www.sands.org.uk) and the Miscarriage Association (www.miscarriageassociation.org.uk), and feedback from professionals to the National Bereavement Care Pathway Lead (https://nbcpathway.org.uk/)

[2] https://www.theguardian.com/society/2020/sep/25/only-23-of-nhs-trusts-letting-birth-partners-stay-for-whole-of-labour-covid

Lack of choice and access to services

Restricted access - Women have reported restrictions to the way they can access health services relating to their pregnancy, often finding A and E is the only route available. Many routine scans and other checks have been cancelled.

Redeployment of staff - Some key staff, such as health visitors, midwives, early pregnancy and maternity staff, have been redeployed during the pandemic, meaning women cannot access the services they need. A recent international study (with 42% of respondents from the UK) showed

- 70% of obstetric units reporting a reduction in antenatal appointments
- 56% reporting a reduction in postnatal appointments.
- 86% reporting a reduction in emergency antenatal presentations, suggesting women may have delayed seeking care during the pandemic.[3]

Lack of information, advice and support - After receiving bad news, information on next steps has been limited in many cases. For example, after experiencing a miscarriage, many women report a lack of information in relation to pain, bleeding, and what to do with pregnancy remains.

Parents also report a lack of aftercare for both physical and mental health after leaving hospital.

Repurposing of bereavement suites - In maternity and neonatal settings a lack of time and available space, with repurposing of bereavement suites for example, has impacted on whether staff can provide opportunities for memory making such as taking footprints, or photographs after a stillbirth or neonatal death. It also means that bereaved families cannot spend time with their babies, which is very damaging to their long-term wellbeing.

Delays in post-mortems – Early in the pandemic parents of stillborn babies were told that post-mortems could not take place and if they did, they were not given an explanation of the results. National guidance has sought to address this and we need to ensure it is followed during a second wave.

Communication challenges

In hospital settings, PPE has been a barrier to the delivery of compassionate care, with staff struggling to communicate in the way they would prefer. Hospitals have reported shortages of face-to-face interpreters to help communicate with women who do not speak English.

After a stillbirth, neonatal or sudden infant death, some families whose baby has had a post-mortem have had the results communicated by post or email, which is not appropriate.

While some new ways of communicating have begun during lockdown, such as virtual antenatal appointments, these are not accessible to all. Not everyone has access to IT, or a safe and private space for virtual consultations. Virtual appointments do not always provide the same reassurance as an in-person scan or consultation, which is particularly important for those pregnant following a previous loss.

The impact of Lockdown

Isolation - The isolation many people experience after pregnancy and baby loss - women, partners, other family members and friends - has increased during lockdown, contributing to negative impacts on women and partners' mental health, and their ability to access support from friends and family, professionals, and community outreach services.

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[3] https://www.rcog.org.uk/en/news/leading-royal-colleges-urge-the-nhs-to-learn-lessons-and-avoid-redeploying-maternity-staff-ahead-of-second-wave/

The effect of Covid-19 restrictions, and in particular social distancing, have had a major impact on access to care and support, and have complicated grief and responses to pregnancy and baby loss. Baby Loss Awareness Alliance members reported huge increases in demand for their services during the first wave, with:

- the Miscarriage Association seeing a 37% increase in direct contacts: phone, email, live chat, direct messaging
- Sands, the stillbirth and neonatal death charity seeing a 65% increase in demand for their helpline
- Petals, the baby loss counselling charity seeing referral figures soaring after they moved their entire specialist counselling service online at the beginning of lockdown.

Risk and inequality

Lockdown has also exacerbated risk factors for some types of baby loss, such as Sudden Unexplained Death in Infancy, which can be linked to deprivation.

Following feedback from Baby Loss Awareness Alliance Members and others on the impact the Government's 'stay at home' messaging was having on attendance at maternity appointments, it was altered to make it clear that maternity services in England are safe and open, and the importance of attending pregnancy appointments. However, in some cases, pregnant women are still not accessing health services for fear of the virus. This is particularly true for women from more disadvantaged communities, where inequalities in access to digital technologies also mean that virtual appointments are less accessible.

It is well known that Black, Asian minority ethnic (BAME) women are more likely to die during pregnancy and shortly after birth, and that their baby is more likely to die[4]. We also know that COVID-19 was found to have a disproportionate impact on pregnant BAME women, with them making up 55% of UK pregnancy hospitalisations at the height of the pandemic[5]. Seven of the ten pregnant women who died of COVID-19 between 1 March and 31 May 2020 were from BAME backgrounds[6].

Collecting data and understanding the impact of the pandemic on pregnancy and baby loss

Work is on-going to understand the full impact of the COVID-19 pandemic across the pregnancy and baby loss spectrum.

We do know that data on baby deaths is not being reported in a timely way by some Trusts to MBRRACE - UK, the national programme for collecting data on stillbirths and neonatal deaths. This means that we do not yet know the full impact of the pandemic on rates of stillbirth and neonatal death, but there is concern that cancelling scans, blood tests and other checks in pregnancy means that some high-risk pregnancies are being missed.

Action needed

The Government must take swift action so that negative consequences can be avoided as infections rise again, in areas of the country that are locked down, and to understand the full impact of the pandemic on those experiencing pregnancy and baby loss by:

[4] MBRRACE, Saving Lives, Improving Mothers' Care, November 2019 - https://www.npeu.ox.ac.uk/assets/downloads/mbrrace-uk/reports/MBRRACE-UK%20Maternal%20Report%202019%20-%20WEB%20VERSION.pdf

[5] The UK Obstetric Surveillance System SARS-CoV-2 Infection in Pregnancy Collaborative Group COVID in pregnancy study, UKOSS (2020) Characteristics and outcomes of pregnant women hospitalised with confirmed SARS-CoV-2 infection in the UK: a national cohort study using the UK Obstetric Surveillance System. https://doi.org/10.1136/bmj.m2107

[6] MBRRACE, Saving Lives, Improving Mothers' Care, March to May 2020 - https://www.npeu.ox.ac.uk/assets/downloads/mbrrace-uk/reports/MBRRACE-UK_Maternal_Report_2020_v10_FINAL.pdf

1. Monitoring the implementation of the Framework[7] to assist NHS trusts to reintroduce access for partners, visitors and other supporters of pregnant women in English pregnancy and maternity services to ensure partners can be involved when pregnancy or baby loss is anticipated or occurs, whether in relation to attendance at scans or appointments.

2. Guaranteeing equity of access to all parents to Neonatal Units by implementing an equivalent framework to assist NHS Trusts to reintroduce access.

3. Ensuring swift reinstatement of the provision of choices for women facing pregnancy or baby loss in all Trusts, including treatment options and interventions, and options after a bereavement to make memories or spend time with their baby. To support this, health services must be advised not to redeploy key professionals such as health visitors and maternity staff in future lockdowns, so that the most vulnerable families are not put at further risk.

4. Disseminating best practice relating to communication to all NHS staff, such as sharing Sands' guidelines on delivering compassionate care while wearing PPE[8], and ensuring key information relating to COVID-19 is provided in as many languages as possible.

5. Taking action across the NHS and DHSC to capture the impact of the pandemic across all settings in order to counteract negative impacts and plan for future lockdowns. This includes gathering swift data on stillbirth rates during the pandemic, and analysing data for any trends in the impact on specific groups such as women from BAME communities. There is also a need for a survey of the mental health impacts of COVID-19 on those bereaved through pregnancy and baby loss in order to plan services for this group into the future.

6. The National Bereavement Care Pathway for Pregnancy and Baby Loss is a key conduit for delivering excellent bereavement care to women and families. All Trusts in England must be encouraged and supported to join up to the Pathway, which will further help to counter some of the negative impacts of COVID-19 that have been highlighted here.

More information & contacts

- Baby Loss Awareness Alliance, Jess Reeves - jessica.reeves@sands.org.uk
- Sands, the stillbirth and neonatal death charity, campaigns@sands.org.uk
- Bliss, the premature and sick baby charity, Beth McCleverty, bmccleverty@bliss.org.uk
- Petals, the baby loss counselling charity, contact@petalscharity.org
- Miscarriage Association - info@miscarriageassociation.org.uk
- Group B Strep Support - info@gbss.org.uk

About the Baby Loss Awareness Alliance

The Baby Loss Awareness Alliance is a group of 90 charities committed to raising awareness of pregnancy and baby loss, providing support to anyone affected by pregnancy loss and the death of a baby, and working with health professionals, services and decision-makers to improve bereavement care and reduce

[7] Produced by NHS England, The Royal College of Obstetricians and Gynaecologists, The Royal College of Midwives and The Society and College of Radiographers - https://www.england.nhs.uk/coronavirus/wp-content/uploads/sites/52/2020/09/par001599-framework-for-the-reintroduction-of-visitors-throughout-maternity-services-sep-2020.pdf

[8] https://sands.org.uk/professionalsprofessional-resources/communication-while-wearing-ppe

preventable deaths. The organisations involved are listed here - https://babyloss-awareness.org/organisations