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House of Commons

London SW1A 0AA

All-Party Parliamentary Group on Baby Loss

Monday 3rd August 2020, 16:00 - 18:00, Via Zoom

MINUTES

Members in attendance:

- Cherilyn Mackrory MP (Chair)
- Jess Faulkner, representing Sharon Hodgson MP

Other guests:

- Aimee Middlemiss University of Exeter
- Alessandro Alagna Liberty's Mother
- Alex Mancini Chelsea and Westminster Trust
- Alyson Chorley Twins Trust
- Alyx Elliott Petals
- Anita Rakhit
- Ann Chalmers Child Bereavement UK
- Annmarie Jackson Cradle
- Beverley Radcliffe The Coroners' Courts Support Service
- Caroline Lee-Davey Bliss
- Caroline Schmeer Peddlestones
- Clea Harmer Sands
- David Monteith Grace in Action
- Dawn Brown Cradle
- Donald Mbeutcha Dope Black Dads
- Emma Brooke Office for National Statistics
- Erin McCloskey Canterbury University
- Fauzia Paize Kings College
- Gemma Quayle Office for National Statistics
- Geoff Heaps Lily Mae Foundation
- Gillian Weaver Human Milk Foundation
- Hannah McConnell Office for National Statistics
- Heidi Eldridge MAMA Academy
- Jane Denton Multiple Births Foundation
- Jane Fisher Antenatal Results and Choices
- Jane Plumb Group B Strep Support
- Jenny Chambers ICP Support
- Jenny Poirier Lullaby Trust

- Jenny Ward Lullaby Trust
- Jessica Clasby-Monk Legacy of Leo
- Jessica Read NHS England
- Jessica Reeves Sands
- Josie Anderson Bliss
- Karen Burgess Petals
- Karen Todd Department for Health and Social Care
- Kate Holmes Lullaby Trust
- Laura Wetherley AbbVie
- Lauren Hutton Imperial College Healthcare NHS Trust
- Leanne Turner Aching Arms
- LeighAnne Wright Little Things & Co
- Lottie King Leo's Neonatal
- Louise Zeniou Cradle
- Lucy K. Smith University of Leicester
- Marcia Jones Lullaby Trust
- Mohamed Omer Gardens of Peace
- Munira Oza Ectopic Pregnancy Trust
- Nikki Crowley Royal College of Paediatrics and Public Health
- Paula Abramson Bereavement Training International
- Penny Kerry The Miscarriage Association
- Rachel Clarke BPAS
- Rich Boyd Twins Trust
- Roopal Shah Babyloss Support LLR
- Ruth Bender-Atik Miscarriage Association
- Ryan Jackson The Lily Mae Foundation
- Sabina Patel Muslim Bereavement Support Service
- Samantha Collinge University Hospitals Coventry & Warwickshire NHS Trust
- Sarah de Malplaquet Kit Tarka Foundation
- Sarah Wilson Lullaby Trust
- Sharon Darke Twins Trust
- Sophie Daniels Liberty's Mother
- Tara Arnold Nova Foundation
- Vicki Robinson Miscarriage Association

1: Welcome, introduction and updates (Cherilyn Mackrory MP, Co-Chair of APPG on Baby Loss) (10 mins)

Cherilyn opened the meeting and welcomed everyone. She introduced herself as the new Co-Chair of the APPG alongside Rt Hon Jeremy Hunt MP, who were both elected at a short EGM in July. She talked about her family's personal experience of baby loss, which drove her to attend January's APPG and stand first as an Officer of the group and now Co-Chair.

Cherilyn went on to explain that this informal APPG meeting was being held during recess due to the exceptional and urgent circumstances of Coronavirus. The meeting was convened specifically to look at the impact of COVID-19 on services relating to baby loss

and to generate some key asks and actions to present to the Secretary of State for Health and Social Care.

Updates: Cherilyn highlighted that three inquiries have recently been announced for attendees to be aware of:

- 1) The House of Commons Justice Committee have launched an inquiry into the Coroner Service in England and Wales. Submissions are welcomed until 2 September.
- 2) The House of Commons Health and Social Care Committee have launched an inquiry into the safety of maternity services in England. The Committee is led by Jeremy Hunt MP, Co-Chair of the APPG on Baby Loss. Submissions are welcomed until 4 September.
- 3) Rt Hon Andrea Leadsom MP has announced an inquiry into the first 1001 days, with a particular focus on reducing inequalities. The review will report in January 2021. Cherilyn is part of a group of MPs feeding into this work, and more information on how to contribute will be made available soon.

2: Impact of COVID-19 on different areas of pregnancy and baby loss

Cherilyn introduced each speaker who then spoke for 5-10 minutes on each part of the pathway.

- Miscarriage, ectopic pregnancy and molar pregnancy
Ruth Bender-Atik, National Director of the Miscarriage Association

Ruth explained that the Miscarriage Association have surveyed their service users to understand the impact of COVID-19. They found clear impacts on reduced access to face to face care, reduced access for partners, reduced options for management of pregnancy loss and reduced information, empathy and follow-up.

For example, 18% of people accessing care were seen via A and E, suggesting that this was their only route to access pregnancy care. Access for partners was severely reduced with some not even able to join scans or consultations via video or speakerphone call. This meant women were having to receive and process bad news and make decisions alone.

There was also an increase in women miscarrying at home, and reports of a lack of information on what to expect when this happened, particularly in relation to pain, bleeding and what to do with pregnancy remains.

There was a reduction in the options provided for interventions after the diagnosis of miscarriage and ectopic pregnancy. While some of these reductions were due to service restrictions, there was also an increase in women choosing not to go into hospital to access services.

Ruth also explained that the Miscarriage Association have been working hard to explain changes to services to women and their partners. They have also moved their support groups online, and plan to continue to offer this service into the future.

Her key concern was that the reductions and restrictions seen in services might become the norm moving forward. Her call to action was to ensure services were reinstated, and pre-COVID services were improved upon. This would include reinstating face-to-face appointments, ensuring partners can be present, and providing the full range of options for women and families. Lastly, Ruth noted that continuing to support and enable the National Bereavement Care Pathway is the way to ensure the best bereavement care.

- Termination of Pregnancy due to Fetal Anomaly
Jane Fisher, Director of Antenatal Results and Choices

Jane explained that the main impact of COVID-19 on ARC's service users has been linked to the involvement of partners. Women are being told bad news when they are alone, and often are unable to have their partner on video or speaker phone during the consultation.

Jane shared the stories of two women who have experienced loss during the pandemic. She noted that while women and families understand why their care has changed, this does not lessen the impact that it has on them.

She further noted the impact of uncertainty, explaining that some women are choosing to end a pregnancy based on an initial finding rather than seeking out confirmatory tests or scans.

She noted that isolation is exacerbating the issues, as women and families are less able to access support from family and friends after a bereavement in the current context. Lastly Jane explained that some women are reticent to come forward for support from ARC, because they do not feel they should prioritise their bereavement in the wider context of COVID and the number of bereavements across wider society.

Jane explained that the ARC team have been working from home so far to keep their services running. Her call to action for a future lockdown would be to ensure better involvement of partners, and to better support the National Bereavement Care Pathway.

- Stillbirth
Clea Harmer, CEO of Sands

Clea explained that Sands had anticipated a number of challenges that might arise from COVID in relation to maternity services and stillbirth care. These include the registration of funerals, support from family and friends, and the impact both on those previously bereaved and those pregnant after a loss.

She noted that all of these had been issues, but there had been additional unanticipated challenges. These included unavoidable changes, such as the wearing of PPE impacting on compassionate care, which should return to normal as soon as possible. They further included unintended consequences, such as the 'stay at home' message dissuading women from accessing maternity services when they needed to, which must be avoided in the case of a second lockdown. Lastly Sands identified new ways of working, such as virtual antenatal appointments, which should be evaluated before potentially being rolled out more widely.

Clea explained that parents' feedback to Sands had been similar to that reported by Ruth and Jane. She noted that healthcare professionals had reported an impact on the space

they had to deliver care, for example with bereavement suites being taken out of use, and a lack of time for key elements of care such as memory making. PPE was identified as a barrier to delivering good care, and Sands have developed a resource to help address this. She further explained that in some case postmortem results had been sent to families via post or email, which is something Sands have been working with the Royal College of Pathologists to address.

For pregnancies after loss, the key impacts have been partners not being able to attend scans or consultations, reassurance scans being cancelled, and virtual antenatal appointments not providing reassurance.

For maternity care, impacts have included mothers with concerns about baby's movements being sent home, scans being cancelled, and parents too frightened to go into hospital.

Some changes have already been seen. For example, the stay at home messaging was amended to encourage women to access maternity services. Sands have also been working with the NHS and Royal Colleges to update guidance.

Clea noted that it is believed that BME people have been disproportionately impacted by the changes to date. However, a key concern is that there is not good enough data on stillbirth rates during the pandemic to understand the full impact. Clea therefore called for improvements in data collection for stillbirth to ensure more real time awareness of any changes in rates. The data collection for stillbirth stands in contrast to that for neonatal death which must be reported within 48 hours.

- Neonatal death
Caroline Lee-Davey, CEO of Bliss

Caroline explained that a big impact of COVID on neonatal services has been on parent experience. Previously parents had 24/7 access to neonatal units, and played a hands on role in care and decision making for their babies. During lockdown, access has been restricted with units often only allowing visits for two hours each day. Further, units allow one parent to visit at a time, or in some cases only allow one parent to visit at all. This often excludes dads or partners from being with their baby.

A knock on effect of these restrictions is that parents have had to make decisions or receive bad news without their partner present. There has been some flexing of these restrictions for babies at the end of life, but not in all cases.

Another key change is the barring of wider family members, such as siblings, from visiting neonatal units. This has meant that sometimes a baby has died with only their parents having been able to meet the baby, impacting on the grieving process.

After a baby dies on the neonatal unit there has been less opportunity for memory making, difficulty arranging funerals, and difficulty registering births and deaths.

There has been a further impact on the psychological support available to parents on the neonatal unit. This was already a challenging area but provision has worsened due to COVID. Outreach support in the community has further been impacted. Parents have further reported an increase in mental health problems, including anxiety and stress.

Bliss have worked to develop new resources for parents to reflect the changes to services. They have moved their support service online, and they are campaigning for greater parental access to units and involvement in care. Caroline noted that Bliss would like to see a minimum acceptable level for parental involvement in case of a second lockdown or future pandemic.

- Sudden Unexpected Death in Infancy up to 12 months
Jenny Ward, CEO of the Lullaby Trust

Jenny explained that lockdown had exacerbated elements that were already risk factors for Sudden Unexpected Death in Infancy (SUDI), such as deprivation, access to support from friends, family, and access to health services which all help with safer sleep advice. The National Child Mortality Database identified SUDI as a risk at the start of lockdown and has been carrying out daily monitoring of data.

Investigations into SUDI have been amended to include a COVID test, however regional variations in the investigations have increased as a result of the pandemic. Investigations that previously took between six months to a year are expected to now take longer, and this impact may last for some time.

The impact on families includes delays to funerals, and an increase in postmortem results being received via post or email. There has been an additional impact on families pregnant after loss, as health visitors have been redeployed. There are concerns that vulnerable families are now in an even more vulnerable position as a result. The longer term impact of this on SUDI rates may not be known for some time.

The Lullaby Trust have moved most of their services online, apart from their family days out which are paused. The charity is concerned that risk factors for SUDI such as deprivation may be heightened into the longer term as a result of the pandemic. There is also a concern about the impact on professionals who are providing bereavement support remotely from home, who need to be able to access supervisions.

3: Discussion

Cherilyn introduced a discussion with wider attendees about the issues raised so far, and other issues of note.

Mohamed Omer from Gardens of Peace echoed Clea's concerns about stillbirth data. He also echoed concerns about a greater impact on people from the BME community. He highlighted some reported delays in hospitals releasing bodies to families or to cemeteries for burial and noted that this was culturally inappropriate for Muslims in particular. He went on to raise concerns about a lack of paediatric coroners which may be contributing to delays. He further noted that a restriction on the number of people who can attend a funeral might impact on how families can access support from their friends and family after a bereavement.

Karen Burgess from Petals noted the mental health impact of COVID for those who have experienced pregnancy or baby loss. She said that Petals have been running their counselling services online and have seen a rise in demand. Moving online has enabled them to extend their reach. She noted that there has been a rise in people reporting

suicidal thoughts and self-harm among those accessing Petals' services. There were particular concerns reported by those who were pregnant after a loss and were anxious about accessing health services. Karen felt that the mental health consequences of the pandemic would last into the long term.

Alex Mancini from Chelsea and Westminster Trust reinforced the impact of separating parents from their babies on neonatal units, and asked what action the APPG could take to address this.

Louise Zeniou from Cradle noted that some parents are accessing scans through private providers, often at weekends, and that they have been working on a pathway to ensure parents can then move into NHS care if they need follow up.

David Monteith from Grace in Action noted that outcomes for BME families were worse before COVID, and so it should not be a surprise that this has continued. He called for greater diversity in guests attending the APPG and those speaking. He further noted the importance of ensuring partners can attend appointments and wider health services.

Donald Mbeutcha from Dope Black Dads echoed David in saying that baby loss rates in the BME community were already high before the pandemic.

Lauren Hutton from Imperial College Trust commented on the impact on people who do not speak English fluently. She explained there have been problems accessing face-to-face interpreters, and that COVID specific information has not been available in different languages.

Rachael Clarke from BPAS noted that the Royal College of Obstetricians and Gynaecologists have been running a study on maternity outcomes among BME people.

Rich Boyd from Twins Trust highlighted that although COVID has increased awareness of bereavement in general, it is important not to lose the focus on baby loss that has been generated in recent years. He also noted that local support charities are closing which will impact on parents' experiences. He suggested working with the APPG on Bereavement to bring a joint focus to these issues.

Jenny Ward echoed sentiments that were raised about increasing the diversity of the APPG. She noted that the meeting is open to all, and advised people to share the appg@lullabytrust.org.uk email with anyone who might like to attend in future. She further noted that baby loss in BME communities is on the agenda for an upcoming meeting, and that many baby loss charities are looking internally about how to improve the reach of their services into different communities.

Jess Read from NHS England expressed her thanks to all the speakers and contributors to the discussion so far. She highlighted four actions that Local Maternity Systems in the NHS in England have been asked to undertake. These are to demonstrate equal access to health services and improved outcomes across BME communities, to increase targeted communications to particular at risk communities, to ensure women of Colour understand the importance of Vitamin D, and to collect better quality data on the ethnicity of service users.

Jane Plumb from Group B Strep Support welcomed the incoming Co-Chairs' mention of prevention in their remarks. She asked how this will translate into activity. Cherilyn noted

that the December meeting is due to focus on learning from data, and how this can lead to prevention. Sarah de Malplaquet from the Kit Tarka Foundation supported the focus on prevention.

Marcia Jones from the Lullaby Trust asked how stakeholders can get more involved with NHS England's work, and Jess shared her email address: jessicaread@nhs.net. Marcia also noted the impact of COVID on different cultural rituals around bereavement, which have affected different communities in different ways.

Sabina Patel from the Muslim Bereavement Support Service noted the importance of using new technologies to connect with bereaved parents. Jane Plumb agreed, but highlighted that not everyone has access to digital technologies. Leanne Turner from Aching Arms explained that the charity has set up a telephone befriending service to tackle this.

Mohamed Omer and Donald Mbeutcha both offered to support guests with providing culturally appropriate literature or training as required.

Jessica Clasby-Monk from the Legacy of Leo noted that it is important to choose inclusive language when talking about partners, in order not to exclude different types of families from accessing services.

Sophie Daniels from Liberty's Mother offered to use her social media links to promote the APPG to a wider audience.

Lauren Hutton offered to share any output from today's meeting with the National Bereavement Midwife Forum which has over 160 members across different Trusts.

4: Any other business and close of meeting

Geoff Heaps from the Lily Mae Foundation raised the issue of Government funding for small charities, which has been allocated differently to funding available to other sectors. Cherilyn agreed to look into this and asked Geoff to email appg@lullabytrust.org.uk with more details. She encouraged any other attendees struggling with this to raise the issue with their local MP to ensure they are aware of the scale of the problem.

Clea Harmer highlighted two challenges relating to MBRRACE-UK. First, the national data opt-out will come into force in September which will reduce the amount of data available for national clinical audits, reducing their validity. Cherilyn agreed to take up this issue.

Secondly, Clea noted that an MBRRACE-UK report had been produced on maternal mortality but that there appeared to be a delay in its publication. Cherilyn agreed to write to NHS England to enquire about this.

David Monteith noted the Aspire group are researching into experiences of pregnancy during COVID. For more information, visit <https://aspire.ucsf.edu/>.

Cherilyn thanked everyone for their attendance and participation, and reiterated her plans to drive the APPG forward in its aims along with her Co-Chair. The next meeting of the APPG is planned for Monday 14 September, 16.00-18.00, location TBC.

Actions: It was agreed that the APPG would undertake the following actions:

- To write up a report of the findings shared at today's meeting including asks for Trusts to implement to improve parent experience, particularly should there be a second wave or lockdown
 - To share this with the Department for Health and Social Care, the Minister for Bereavement, and with local MPs who are in a position to influence their local Trusts
 - To also share it with NHS England
- To write to NHS England in relation to the MBRRACE-UK report [this report has since been published]
- To look into how to include MBRRACE-UK data in the exemptions to the national data opt-out.

There are two outstanding actions from January's APPG meeting to be completed:

- To consider the APPG's presence on social media
- To write to DHSC to ask for a mid-point update on progress against the National Ambition and plans for the next five years.