



**House of Commons**  
London SW1A 0AA  
**All-Party Parliamentary Group on Baby Loss**

**Monday 28<sup>th</sup> October 2019**

**16:00 - 18:00**

**Commons Committee Room 15, House of Commons**

**MINUTES**

**Members in attendance:**

- Antoinette Sandbach MP (Chair)
- Sir George Howarth MP
- Victoria Prentis MP

**Guests:**

- Alyx Elliott - Petals
- Amy Taylor - CMV Action
- Chris Reid - Teddy's Wish
- Clea Harmer - Sands
- Corrina Taylor - Liberty's Mother
- Elizabeth Hutton - Kicks Count
- Francesca Day - Department of Health and Social Care
- Gillian Weaver - Human Milk Foundation
- Jane Scott - Imperial College NHS Trust
- Jenny Ward – The Lullaby Trust
- Jess Read - NHS England
- Jess Reeves - Sands
- Josie Anderson - Bliss
- Karen Burgess - Petals
- Karen Todd - Department of Health and Social Care
- Kate Mulley - Sands
- Lauren Hutton - Imperial College NHS Trust
- Leanne Turner - Aching Arms
- LeighAnne Wright - Little Things and Co
- Maiya Smith - Liberty's Mother
- Marc Harder - Sands

- Marie Trueman-Abel, Newham CCG
- Matt Wright - Little Things and Co
- Oliver Plumb - Group B Strep Support
- Paula Abramson - Bereavement Training International
- Penny Kerry - Miscarriage Association
- Sam Collinge - UHCW NHS Trust
- Sophie Daniels - Liberty's Mother
- Tara Arnold - Nova Foundation
- Zoe Moulton - RCOG

## **1. Welcome and introductions (Antoinette Sandbach MP, Chair of APPG on Baby Loss)**

Antoinette opened the meeting and welcomed everyone. She reported that the APPG had a new Secretariat, Caroline Stickland, who is looking forward to meeting everyone at a future meeting. Caroline can be contacted on the normal email address: [appg@lullabytrust.org.uk](mailto:appg@lullabytrust.org.uk).

## **2. Updates (Antoinette Sandbach MP)**

- **New Government and reshuffle of Ministerial responsibilities**

Antoinette explained that in July 2019, Boris Johnson became Prime Minister and carried out a reshuffle of Ministers. Matt Hancock MP has remained in post as Secretary of State for Health and Social Care, but there is a new Minister responsible for maternity services. This is Nadine Dorries MP, whose full title is Parliamentary Under Secretary of State for Mental Health, Suicide Prevention and Patient Safety. Nadine Dorries was due to attend the planned APPG meeting in December, however this is under review due to the likelihood of a December General Election.

- **Update on the Children's Funeral Fund for England**

The Children's Funeral Fund for England came into effect on Tuesday 23<sup>rd</sup> July. The fund covers the costs of cremation or burial fees for children under the age of 18. It is not means tested, and is available to all parents regardless of nationality or residency. A further contribution of £300 is available to be put towards the price of a coffin, shroud or casket. The fund has been established by the Government in memory of Martin, the son of Carolyn Harris MP. Antoinette highlighted that many funeral directors already will not charge anything for a child's funeral.

- **Update on latest annual data for stillbirth, neonatal death and SIDS**

Antoinette reported that the Office for National Statistics published 2018 data on stillbirths and neonatal deaths in England this August. The stillbirth rate has fallen from 4.1 per 1,000 births in 2017 to 4.0 in 2018. The neonatal mortality rate has fallen from 2.9 deaths

per 1,000 births in 2017 to 2.8 in 2018. In Wales the stillbirth rate was 4.4, and the neonatal mortality rate 2.5.

The ONS has forecast that to meet the Government's ambition to halve stillbirth and neonatal mortality rates in England by 2025, the rates in 2025 will need to fall to 2.6 stillbirths per 1,000 births, and 1.5 neonatal deaths per 1,000 births.

Data has also been published on unexplained infant deaths in England and Wales for 2017. The unexplained infant mortality rate has decreased to 0.27 deaths per 1,000 births, the lowest on record. Antoinette welcomed the good news across all these data but noted that there is still work to do.

### **3. Update on the 'Liberty's Mother' song project (Sophie Daniels)**

Sophie Daniels updated the meeting on her project, 'Liberty's Mother', a song which she wrote for her daughter Liberty and played at the memorial service during Baby Loss Awareness Week 2018. She described the background to her project and reported that the video is on youtube now. Everyone is invited to watch the video, share and comment to help raise awareness of baby loss. Her project also seeks to give a positive vision for the future and to raise funds for Tommy's. She is developing more videos and merchandise, which will be available through the Sands website.

Since launching the video she has reached 50,000 people, been featured in the press and on radio stations. Sophie is happy to be contacted about events via [hello@libertysmother.com](mailto:hello@libertysmother.com). There was a discussion about whether families could use the song at funerals, and Sophie said families could play the song or use sheet music.

### **4. Update on the National Bereavement Care Pathway training programme (Marc Harder, National Bereavement Care Pathway Lead, Sands)**

Marc Harder, National Bereavement Care Pathway Lead at Sands, gave an update on the rollout of the Pathway, including new workshops and online training. He thanked all those on the APPG and guests who have supported the Pathway so far. Over 100 sites have engaged with the programme, either adopting the Pathway or in the process of signing up. There is still work to do to encourage take up. He is beginning a programme of workshops for professionals across the country.

Marc updated everyone on the new online Pathway training. This consists of two modules, one is a 10 minute introduction, the second is a 30 minute session for professionals going into more detail. Over 250 modules have been completed so far since the end of September. Everyone is invited to promote the training in their networks.

Marc also set out the next steps for the Pathway, including to roll out the workshops, to get more Trusts adopting the Pathway, to expand in Scotland and to develop a 'Champions' network.

Antoinette noted that everyone can help to encourage their local NHS Trusts to adopt the Pathway standards. New MPs should be encouraged to put pressure on local services too. Antoinette then asked for questions from the floor.

Sam Collinge (UHCW NHS Trust) noted that the workshops will be welcome as midwives in her area would like more information and to talk more about the Pathway. She asked if there was a job description for the bereavement lead. Kate Mulley (Sands) explained that there is a document in production that sets out what the leadership elements of the role look like, and this will be available online soon.

Leanne Turner (Aching Arms) asked if she could include information about the Pathway in her organisation's training. Marc said there were fliers and slides available for this.

Antoinette and Victoria Prentis MP both highlighted the importance of writing to the local MP if Trusts don't engage with the Pathway. Antoinette also asked guests to write directly to her to highlight any such issues.

Jess Read (NHS England) said she would link up with Marc to follow up with Trusts in London.

## **5. Psychological support after baby loss**

- **Presentation of Baby Loss Awareness Alliance report: Out of sight, out of mind (Jessica Reeves, Public Affairs and Campaigns Manager, Sands)**

Jessica Reeves from Sands presented the Alliance's [new report](#) on psychological support after baby loss. This report was released at the beginning of Baby Loss Awareness Week 2019.

She began by sharing the story of Cheryl Gadsby, a bereaved parent who is also a member of the National Bereavement Care Pathway steering group. Cheryl's story is shared with her permission:

"I have spent some time listening to the parliamentary debate and have been gladdened to see that the focus for baby loss awareness week and indeed the debate has been the ongoing mental health support for parents. I am a bereaved parent who sits on the APPG (although have been unable to attend more than a couple of meetings) and am a member of the parent advisory panel for the National Bereavement Care Pathway. I feel strongly that psychological support after the loss of a baby is important and am encouraged that this next step in improving the care for bereaved parents is being taken.

I developed PTSD following the loss of our daughter Rachel. The hospital had a bereavement midwife who arranged for us to speak with her very soon after our loss. However, I could only manage one meeting with her as we had to return to the hospital and walk through the maternity unit in order to see her. I had been very ill in hospital for six weeks, losing our baby four weeks into this time. It was too much for me to cope with to return to the hospital. I carried on for a year trying to manage on my own but eventually my husband and I were so concerned about the

deterioration of my mental health that we accepted that I needed some outside support. I tried to access the NHS mental health services but found this incredibly unhelpful. The counsellor I spoke to just couldn't understand what I was explaining, didn't know what pre-eclampsia was and couldn't quite understand why I was so upset about the loss of our baby. Thankfully we were able to afford to see a wonderful baby loss counsellor locally on a private basis. I just don't know what I would have done if we hadn't had the money to do this.

The support I received has helped me to function again and, four years later, I am now working as a nurse and coping with being back in a high pressured, hospital based environment. It concerns me, following the excellent work on the NBCP, that when a couple leave hospital that support can be patchy and they can feel left on their own. It is so important to ensure that every couple is able to receive the support that they need, regardless of their ability to pay but also in an environment that is helpful for them. I do not think that it is acceptable for families to have to return to the hospital and indeed the maternity unit where they lost their child. To have to walk past pregnant women or come across newborn babies and their families in the lift or to see the posters about birth and newborns on the walls is just too distressing.

I work as a cardiac nurse and every patient who undergoes major heart surgery, stent insertions or a heart attack are automatically referred for cardiac rehabilitation. This gives them support to improve their physical health and recover from their operation but also psychological support. It is acknowledged that what they have been through is a major life changing event and so they will need support to recover from it. It would be wonderful if baby loss was treated the same way and families were automatically referred for help and support. It would reassure parents that they are allowed to grieve and struggle after the loss and that this is quite normal. It would go some way to breaking the silence too.”

Jessica then set out the top level ask from the new report, that governments ensure access to specialist psychological support to all who need it after pregnancy or baby loss. She noted that there is a need for referral pathways, timely access, and good quality services. She set out the new research findings in the report, and also gave examples of areas of good practice.

Antoinette thanked Jessica for her presentation and highlighted the great work happening at Alder Hey in this area to ensure free support is accessible.

- **Presentation of Petals report: Life after loss (Alyx Elliott, Director of Strategy, Petals and Karen Burgess, CEO, Petals)**

Alyx Elliott and Karen Burgess from Petals presented the 'Life after loss' report which was recently published in partnership with the Centre for Mental Health. Karen explained that the Petals counselling service has supported 2,500 parents with positive feedback. They partnered with the Centre for Mental Health to look at the economic case for their service. Karen highlighted that the number of people with clinically defined mental health issues fell from 67.4% to 10% after receiving specialist counselling.

Alyx noted that bereaved parents need specialist support, and that this could save £8.6m against a counselling cost of £3.2m.

Antoinette welcomed the report and agreed it illustrate why mental health support for bereaved parents is so important. She noted that it is rare for parents, especially women, to return to work after baby loss. She then invited guests to discuss the two presentations.

Chris Reid (Teddy's Wish) agreed that support is important, not just right after a loss but longer-term, and it's important to be told that your response is normal. He spoke about his organisation's work to get people to talk to bereaved parents. Community support is important as well as NHS support.

Other guests agreed that the presentation highlighted the importance of support. They discussed challenges of GPs prescribing anti-depressants or sleeping tablets rather than counselling. Others had been told that support was only available for parents with a live baby, and that while midwives were supportive they found help from GPs to be less available.

Antoinette noted that the National Bereavement Pathway was started in the acute setting but that is needed to spread to the community. She said that more training will be needed, and encouraged charities to campaign for this.

Penny Kerry (Miscarriage Association) said that including figures for miscarriage into the Petals work would make the case even stronger.

Jenny Ward (The Lullaby Trust) noted that bereaved parents in crisis could contacts any one of the charities in the room. No-one should feel that help is not available, and charities are very experienced in supporting bereaved families.

Everyone agreed that charities, parents and professionals should come together to continue making the case locally and nationally for the importance of psychological support.

## **6. Review of Baby Loss Awareness Week 2019 (Dr Clea Harmer, CEO, Sands)**

- **Review of BLAW activity across the UK from the Baby Loss Awareness Alliance**

Dr Clea Harmer from Sands outlined activity from this year's Baby Loss Awareness Week across the UK. She noted that her presentation set out the topline data, as information is still being collated. 89 organisations were involved in the Alliance with the key aims of commemoration, raising awareness, and calling for improvements. Key aspects of the Week included a commemorative online mosaic, local events, and buildings being lit up pink and blue. Clea thanked Antoinette with securing more buildings this year.

Clea also noted that the 'Wave of Light' was the top trend on Twitter in the UK at the end of Baby Loss Awareness Week, part of a huge increase in awareness on social media. There was lots of media interest, including relating to new celebrity ambassadors.

24 MPs spoke in the Parliamentary debate, and the Minister (Nadine Dorries MP) announced that part of new funding for mental health will go to bereaved parents. Clea

thanked the APPG and Antoinette for all their work leading to increased engagement and impact across Baby Loss Awareness Week this year.

Clea further thanked Antoinette, on behalf of all those present at the APPG and involved in Baby Loss Awareness Week more widely, for her passion and commitment over the years which have been integral to the growth of the Week, shining a light on baby loss and the issues that bereaved parents face.

## **7. Any other business**

- MBRRACE-UK seeking proposals for new confidential enquiry topics

The Department of Health and Social Care have asked the APPG to highlight the MBRRACE-UK call for new confidential enquiry topics for severe maternal morbidity, and perinatal morbidity and mortality. The confidential enquiries involve review of cases against national guidelines and standards to assess the quality of care women and their babies received. The deadline for topic submissions is 30<sup>th</sup> November 2019, and anyone (public and professional) can propose a topic for consideration. More information is available on the MBRRACE-UK website: <https://www.npeu.ox.ac.uk/mbrance-uk/topics>

- Pregnancy Loss Review update

Sam Collinge (UHCW NHS Trust) updated that the Review report is drafted, but somewhat delayed due to the relevant officials being moved to work on other projects. She hoped that publication would be between March and May 2020.

## **8. Next meeting: To be confirmed**