All-Party Parliamentary Groups on Baby Loss and Maternity

Meeting notes

- **Date:** 20 October 2025
- **Time:** 15:00-17:00
- **Location:** Committee Room 6, Palace of Westminster
- **Chair:** Andy MacNae MP

Members and representatives in attendance:

- Alison Bennett MP
- Andy MacNae MP
- Baroness Gillian Merron
- Michelle Welsh MP
- Sharon Hodgson MP
- Tessa Munt MP

Speakers:

- Baroness Gillian Merron, Parliamentary Under-Secretary of State for Women's Health and Mental Health
- Alicia Burnett, Black Baby Loss Awareness Week
- Ayesha Anandji Demetriou, bereaved parent
- Bex Walsh, Bereavement Lead Midwife at the Royal United Hospitals Bath, NHS Foundation Trust

- Chris Binnie, Bereaved parent and lived experience expert on bereavement care
- Clea Harmer, Chief Executive Sands
- Kate Brintworth, Chief Midwifery Officer for England
- Michelle Welsh MP, Chair of the APPG on Maternity

Attendees:

- Aimee Green, Luna's Fund
- Alexander Demetriou, Sands
- Angela Thompson, UHDB Bereavement midwife
- Anna Marie Fisher, bereaved family member
- Bex Gunn, The Worst Girl Gang Ever Foundation
- Carly Williams, Zephyrs
- Celeste Pergolizzi, Tommy's
- Clare Livingstone, Royal College of Midwives
- Deborah Persaud, DHSC
- Fiona Gosden, Time Norfolk
- Gillian Rudd, Lily Mae Foundation
- Grace Banham, Colours of a Rainbow and Lancashire Mind
- Jane Plumb, Group B Strep
- Jenny Ward, Lullaby Trust
- Julie Jones, UWL
- Karen Burgess, Petals
- Kate Davis, DHSC
- Kate Marsh, Tommy's
- Kath Abrahams, Tommys
- Laura Buckingham, The Worst Girl Gang Ever Foundation
- Laura Welsh, ARC
- Leanne Turner, Aching Arms
- Leila Hobart, Little Wings of Hope
- Lucy Hardy, Epsom and St Heliers
- Lyndsey Morrit, Sands
- Mia Terra St Hill, Dods
- Munira Oza, Ectopic Pregnancy Trust
- Oliver Plumb, Group B Strep
- Paula Mothersole, Petals
- Peter Mancktelow, Dods

- Peter Reeves, Ebony Bonds
- Poppy Walker, Daphne and Friends
- Racheal Crane, Max's Legacy
- Rachel Burrell, Ebony Bonds
- Rebecca Ashley, Sands
- Ryan Jackson, Lily Mae Foundation
- Sam Collinge, Specialist bereavement midwife and co-chair and co-author of the Pregnancy Loss Review
- Sharon Darke, Footprints Baby Loss
- Sharon Luca, The Luca Foundation
- Sian Ness, Cuddle Cot
- Vicki Robinson, Miscarriage Association
- Zoe Clark-Coats, Mariposa International

1. Welcome & introductions

Andy opened the meeting and welcomed everyone attending.

2. APPG on Baby Loss and APPG on Maternity updates

Andy opened the meeting by reflecting on the recent baby loss debate:

Baby loss debate

Andy opened the meeting by reflecting on the recent parliamentary debate on baby loss, describing it as powerful and timely. He emphasised that the debate left no doubt about the urgency and importance of addressing issues in maternity and bereavement care, and that the presence of forty MPs late into the evening demonstrated a shared commitment across Parliament to drive meaningful change.

Andy also reflected on the significance of Secretary of State Wes Streeting attending the debate, noting that he stayed for three hours and gave a powerful response at midnight. Andy said this underscored the seriousness with which the issue is being taken and highlighted the importance of the lived experiences shared during the debate.

3. Reflections on bereavement care

Andy then shared his reflections on the importance of bereavement care and the role of the APPG in establishing the National Bereavement Care Pathway (NBCP). He shared personal experiences of bereavement care following baby loss and highlighted the gaps in long-term support, particularly for partners.

He stressed the need for consistent implementation of bereavement services across trusts and reiterated the urgency of systemic change related to the consistency and standards of bereavement care.

Andy then introduced Baroness Merron to speak about the importance of bereavement care.

4. Address from Baroness Merron, Parliamentary Under-Secretary of State for Women's Health and Mental Health

Baroness Merron expressed deep gratitude to the APPG and the families who shared their personal stories, acknowledging the courage it takes to speak about baby loss. She emphasised that Baby Loss Awareness Week, while important, should not be the only time these issues are addressed, and that improving care must be a year-round priority.

She affirmed the government's commitment to action, referencing the announcement of an independent inquiry in Leeds, alongside the maternity investigation led by Baroness Amos and the task force chaired by Wes Streeting to ensure meaningful change.

She also highlighted the uneven implementation of the National Bereavement Care Pathway (NBCP) and the need for consistent, culturally competent care across all trusts. She praised the work of Sands in developing the pathway and called for faster, more consistent adoption across the country.

She also stressed the importance of equitable and culturally competent care and the importance of mental health support for fathers and partners.

Baroness Merron closed by reaffirming her personal commitment to this issue, thanking everyone present for their contributions and advocacy.

5. Panel discussion

Andy then moved to the panel discussion, asking speakers to introduce themselves before moving to their contributions.

<u>Clea Harmer, Chief Executive Sands</u>

Clea began by expressing her passion for improving bereavement care and her pride in Sands' leadership role in developing the National Bereavement Care Pathway (NBCP), alongside other charities, and royal colleges.

She explained that the NBCP was initiated through the APPG and piloted with government support and although it has since been voluntarily adopted by every NHS Trust in England, its implementation remains inconsistent.

She then stressed that bereavement care is not just about easing grief—it has long-term implications for mental health, future pregnancies, and the overall wellbeing of families. She warned that poor bereavement care can lead to prolonged trauma, delayed learning, and increased complaints, which place additional strain on the NHS and could be avoided with proper support.

Clea described the NBCP's nine standards, which address the needs of parents, professionals, and the wider healthcare system, and noted that bereavement care was a top concern raised during NHS consultations with parents.

She praised bereavement staff across the country for their dedication, often working beyond their roles and without sufficient support from hospital leadership. She pointed out that excellent care is often delivered despite systemic barriers, and that this reliance on individual effort is unsustainable and unfair. She emphasised the need for equitable care, noting that factors such as geography and background can affect the quality of support families receive.

She illustrated the impact of good versus poor care by sharing two contrasting parent testimonials—one describing abandonment and spiralling mental health, the other praising ongoing support from a bereavement midwife months after the loss.

Clea concluded by calling for a ministerial directive to mandate the NBCP in England, arguing that this would improve outcomes for families, support staff, and strengthen the healthcare system overall.

<u>Alicia Burnett, Black Baby Loss Awareness Week</u>

Alicia began by expressing her desire to move beyond statistics about Black maternal and infant loss, focusing instead on the urgent need for action and change. She shared her personal frustration and emotional exhaustion from repeatedly telling her story without seeing meaningful progress, describing how this retraumatises bereaved parents.

Shet introduced the Equitable Bereavement Care Conference taking place in November, which she founded to give Black and Asian bereaved parents a platform to share their experiences and influence change.

The conference aims to go beyond hospital settings, involving social care, extended families, and third-sector organisations, and includes contributions from clinicians and researchers working to improve outcomes.

Alicia then highlighted the importance of co-produced care, where bereaved parents are actively involved in designing services, and criticised the frequent exclusion of Black service users from such processes. She shared an example of a Black woman placed in front of a poster stating she was more likely to die, illustrating how messaging can be traumatising when not paired with evidence of support.

She stressed the need for culturally sensitive care that is personalised and informed by local community engagement, rather than based on assumptions or stereotypes. She also called for better awareness and signposting of community and peer support groups, especially those formed by bereaved parents and tailored to specific cultural needs.

Alicia closed by emphasising that good bereavement care must be courageous, especially in a climate where advocating for marginalised voices can be difficult or politically sensitive.

Michelle Welsh MP, Chair of the APPG on Maternity

Michelle began by describing bereavement care in the UK as a "postcode lottery," where the quality of support varies drastically depending on location. She shared an example of a bereaved father who was left without food, support, or a place to rest for 48 hours after the death of his child.

She criticised the systemic failures that allows such neglect to occur, arguing that the system is broken and that bereaved families are often forced to repeatedly share their trauma just to receive answers. She also highlighted the lack of consistent implementation of the National Bereavement Care Pathway (NBCP), noting that while all trusts have signed up, actual delivery is uneven and often deprioritised.

Michelle then called for the NBCP to be mandated nationally, with proper funding and training for staff to ensure it can be delivered effectively and compassionately. She emphasised the need to support healthcare professionals, recognising that poor care is sometimes the result of staff being overstretched, undertrained, or unsupported.

Michelle closed by outlining that bereavement care must be treated as a national priority and that the government must take responsibility for ensuring equitable care across all trusts. She pointed to Scotland as a model of best practice, where the NBCP has been mandated and prioritised, and urged England to follow suit.

Ayesha Anandji Demetriou, bereaved parent

Ayesha shared a personal account of her experience of miscarriage, and the inadequate care and lack of compassion she received.

She recounted how, after experiencing spotting, she and her husband were passed between services including 111, her GP, and the early pregnancy unit, none of which provided timely or appropriate support. At the hospital, she was told there were no sonographers available and advised to wait in A&E for over five hours.

Ayesha outlined that when she finally received a scan, she discovered she was carrying twins but was then informed there were no heartbeats. The news was delivered without sensitivity, and she was placed in a dimly lit room with minimal support.

She described being handed leaflets and left alone with her husband, with no follow-up, no mental health referral, and no one to check on her wellbeing in the days that followed. She also highlighted the emotional toll of having to research the risks of an MCMA twin pregnancy after the loss, and the injustice of having to educate herself while grieving.

Ayesha criticised the lack of continuity and communication between services, and the absence of compassionate care throughout her experience. She emphasised that all medical staff must be equipped to support bereaved parents, as bereavement often occurs outside of the maternity wards.

Ayesha called for universal implementation of the National Bereavement Care Pathway (NBCP), stressing that compassionate, individualised care must be available to all families.

Bex Walsh, Bereavement Lead Midwife at the Royal United Hospitals Bath, NHS Foundation Trust

Bex introduced herself as a bereavement midwife who has been working in the role since her hospital participated in the pilot for the National Bereavement Care Pathway (NBCP) in 2018.

She described her involvement in supporting her local maternity system to adopt the NBCP and her work facilitating a regional bereavement forum in the South West, which provides peer support and training.

Bex is also part of the NBCP Professional Advisory Group, where she contributes insights from frontline practice to inform national guidance and policy.

She emphasised that good bereavement care relies on collaboration across departments, including maternity, neonatal, mental health, spiritual care, and outpatient services.

Bex highlighted the lack of specific training requirements, which makes it difficult to advocate for time and resources within hospital leadership structures.

While she praised the passion of individual staff members, Bex stressed that passion alone is not enough—regular, up-to-date, and mandated training is essential to ensure consistent and meaningful care. She called for clear national standards that allow flexibility but provide enforceable expectations.

Bex explained that bereavement care must be psychologically safe for staff as well as families, noting that many healthcare workers have personal experiences of baby loss and need support when delivering care.

She shared that she meets every bereaved family in her trust, including those experiencing early loss, termination for medical reasons, stillbirth, neonatal death, and sudden infant death. This gives her a unique perspective on the diversity of grief and the gaps in support.

She also emphasised the importance of individualised care that respects cultural backgrounds and personal circumstances, and the need to include bereavement midwives in more national forums and decision-making spaces.

Bex concluded by stating that while bereavement care cannot fix the tragedy of loss, it can help families function and carry their grief forwards. Her goal is to ensure that every family she meets receives compassionate and effective support.

Chris Binnie, Bereaved parent and lived experience expert on bereavement care

Chris spoke about the emotional impact of baby loss, describing how every interaction with the healthcare system has the power to either support healing or compound grief.

He highlighted the importance of continuity, honesty, and compassion in bereavement care, stating that families need someone to take responsibility and “stay” with them through the process.

Chris warned against the secondary trauma that occurs when families are ignored, dismissed, or left to chase answers, and stressed that trust is built through thoughtful, proactive care.

Chris explained how good bereavement care can transform the worst experience imaginable into something survivable, helping families find a measure of peace and begin to rebuild. He described a virtuous cycle: compassionate care builds trust, trust enables honest engagement, and honest engagement leads to better reviews and systemic learning.

Chris argued that family experiences must be central to investigations and reviews, as they complete the picture and bring human context to technical findings.

He used the metaphor of kintsugi, the Japanese art of repairing broken pottery with gold, to illustrate how compassionate care can help families hold themselves together, even after being shattered by loss.

Chris concluded by stating that bereavement care is not just a clinical issue, but it is the golden thread that runs through maternity services, holding together families, practitioners, and systems alike.

Kate Brintworth, Chief Midwifery Officer for England

Kate began by acknowledging the profound human experience of having a child and the ripple effect that baby loss has across families and communities. She emphasised that the impact of bereavement lasts a lifetime.

Kate stressed the importance of listening to bereaved families and understanding what makes a good bereavement service, noting that this insight must guide NHS policy and practice.

She praised the work of Sands and other partners in developing the National Bereavement Care Pathway (NBCP) and highlighted the importance of defining what “good” looks like in bereavement care.

She also spoke about the need to challenge the culture in maternity services where baby loss is sometimes seen as inevitable and instead called for curiosity, accountability, and rigorous investigation when things go wrong.

Kate acknowledged the role of service users in shaping guidance and policy, sharing that she has been personally challenged and inspired by their insights, which have helped her reflect on her own practice.

Kate discussed the expansion of perinatal mental health services, but noted more needs to be done, especially to support fathers and partners. She described how maternity care is evolving to be more inclusive of the whole

family, recognising the needs of both parents and ensuring compassionate care at every stage.

She highlighted the importance of small gestures and thoughtful interactions in bereavement care, stating that every midwife and obstetrician has a responsibility to deliver kindness and empathy.

Kate concluded by reaffirming her commitment, alongside NHS leadership, to stimulate passion, curiosity, and continuous improvement in bereavement care.

6. Moderated Q&A

Andy then moved to the moderated Q&A section of the event:

Question: “How can we address the high turnover of bereavement midwives and ensure they are better supported? Are steps being taken to standardise resources across NHS trusts and provide round-the-clock access to trained bereavement midwives? (**Sian Ness, Cuddle Cot**)

Bex responded that good support for midwives from people trained in baby loss is key and that seeing the difference you are making as a bereavement midwife is restorative when you are properly supported to do so.

Question: What are your thoughts on the importance of having separate waiting areas or spaces for families receiving difficult news during scans? (**Laura Buckingham, The Worst Girl Gang Ever Foundation**)

Chris discussed importance of creating healing environments for families receiving bad news, outlined that every detail in these spaces matters from the artwork on the walls to the names of the rooms, and that these elements should be designed to be comforting, non-triggering, and emotionally safe.

The panel also emphasised that such spaces should be located as far away as possible from areas where sounds or sights might be distressing to grieving families, such as the cries of newborns or busy clinical activity.

Andy raised the example of the Serenity Suite at East Lancashire Hospitals as an example of a good bereavement room.

Question: How can NHS trusts better engage with grassroots organisations like Ebony Bonds, Black Mamas Matter, and Aching Arms to bridge the trust gap between Black families and services? (**Rachel Burrell, Ebony Bonds**)

Rachel raised concerns about the repeated trauma experienced by bereaved families who must continually retell their stories to be heard.

She emphasised the trust gap between families and healthcare services, particularly for marginalised communities and the need for better engagement between NHS trusts and grassroots organisations like Ebony Bonds. She highlighted the importance of building relationships at the local level.

Kate acknowledged the importance of Rachel's question and agreed that engagement with grassroots organisations is essential to bridging the trust gap between families and healthcare services. She outlined that NHS England has structures in place to facilitate this, such as the Stakeholder Council and the Maternity and Neonatal Board, which are designed to challenge decision-making and ensure that service users voices are heard.

Kate also highlighted the need for leadership development, particularly among underrepresented groups. She noted that while London has made progress, with 45% of senior maternity leaders being from diverse backgrounds, this is not consistent across the country. She stressed that local leadership must understand the diversity of their communities and be equipped to engage meaningfully with grassroots organisations.

Michelle highlighted the need for this engagement and consultation to take place and for systems wide change to engage communities.

7. Questions from the room

Andy then moved to questions from the room in the remaining time:

Leanne Turner (Aching Arms) highlighted the role being played by the charities set up by bereaved parents who have been filling gaps in services for years and encouraged the APPG and Government to consult with these organisations.

Sam Collinge (Lead Bereavement Midwife) expressed frustration over the lack of progress despite years of advocacy and numerous recommendations. She questioned what has happened to the implementation of the recommendations from the Independent Pregnancy Loss Review.

Andy agreed and stated that this is what the maternity investigation aims to challenge by focusing on actions rather than further recommendations,

8. Meeting close

Andy and **Michelle** thanked those who attended the meeting and the speakers.

Andy closed the meeting and confirmed that the Secretariat will be in touch about the next meeting in due course.