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House of Commons

London SW1A 0AA

The All-Party Parliamentary Group on Baby Loss

17:30 – 19:30, Tuesday 12th July 2016

Room C, 1 Parliament Street

CO-CHAIRS' NOTES

Attendees

APPG members:

1. Antoinette Sandbach MP (Co-Chair) – Conservatives
2. Will Quince MP (Co-Chair) – Conservatives
3. Victoria Prentis MP (Vice-Chair) - Conservatives

External guests:

Speaking:

4. Ben Gummer MP - Parliamentary Under Secretary of State for Care Quality
5. Dr Alexander Heazell - Senior Clinical Lecturer in Obstetrics, University of Manchester
6. Vicky Holmes - Bereavement Midwife, Central Manchester University Hospitals NHS Foundation Trust
7. Francine Bates - CEO, The Lullaby Trust

Attending:

8. Amy Hawkes, Policy Advisor, Maternity Safety Programme, Department of Health
9. Catharine Gammie – Office of Victoria Prentis MP
10. Cheryl Titherly - Improving Bereavement Care Manager, Sands
11. Chris van D'Arqot, Lead Chaplain, Doncaster and Bassetlaw Hospitals NHS Trust
12. Dr Jessica Farren - Specialist trainee in Obstetrics and Gynaecology at St Mary's Hospital, and MD Clinical Research Fellow at Imperial College
13. Dr Maya Al-Memar – Obstetrician Gynaecologist, Imperial College
14. Dr Nina Wilson – Chair, Petals Charity
15. Drew Lindon - Director, Drew Lindon Consulting (minutes)
16. Emily Harris - Office of Victoria Prentis MP
17. Jane Denton – CEO, Multiple Births Foundation
18. Jane Plumb – CEO, Group B Strep Support
19. Jane Scott – Senior Bereavement Midwife, Imperial Hospital
20. Jessica Farrar - Queen Charlotte's Hospital/Tommy's Miscarriage Centre
21. Karen Burgess – CEO, Petals Charity
22. Keith Reed – Tamba

23. Leanne Turner – Coordinator/Trustee, Aching Arms
24. Munira Oza – Director, The Ectopic Pregnancy Trust
25. Dr Nina Wilson - Chair, Petals Charity
26. Nicola Kerry - Midwife/Supervisor of Midwives, Doncaster and Bassetlaw Hospitals NHS Trust
27. Paula Steele – St Georges Hospital (StGH)
28. Penny Kenny – Chair, The Miscarriage Association
29. Sam Collinge – Bereavement Support Specialist Midwife, University Hospitals Coventry and Warwickshire NHS Trust
30. Sarah Martindale - shadowing Antoinette Sandbach MP
31. Shona Cleland – Senior Policy and Public Affairs Officer, Bliss
32. Vanessa Higham – Parliamentary Assistant to Antoinette Sandbach MP

Apologies:

- Ann Chalmers – CEO, Child Bereavement UK
- Lord Boswell of Aynho (Officer) - Non-affiliated
- Gabrielle Osrin – Trustee, Lullaby Trust
- Jane Fisher – CEO, ARC
- Marcia Jones – Helpline Advisor, Lullaby Trust

1. Welcome and introductions

Antoinette Sandbach MP welcomed the attendees.

2. Actions from last meeting

- **Approval of minutes**

Antoinette Sanbach MP asked for any amendments to the 20th April meeting minutes. There were none, and the minutes were approved.

- **Clarification on APPG scope**

Antoinette clarified that the group's remit includes the needs of parents bereaved after a termination for foetal anomaly, following an email query from Jane Fisher, Director of ARC after the last meeting.

3. APPG & Department of Health collaboration (Ben Gummer MP, Care Quality Minister)

Antoinette welcomed the Minister for Care Quality, Ben Gummer MP to the meeting.

The Minister said that it was a great pleasure to attend the meeting. There are not many times in politics when you feel you can attack a problem and have a realistic prospect of making clear progress. The Minister lauded the adjournment debate on stillbirth called by Will Quince MP in June this year, which had been an excellent means of bringing attention to this issue in Parliament.

The Minister said that the APPG is doing the "business of parliament", bringing key issues of concern to constituents to the fore and dealing with them. The APPG has a "really punchy" work programme to address both the prevention of baby loss, and offering the best possible care to parents when this has happened. The Minister explained that he had been engaged from this APPG's formation, and helped sketch out what could be done by the APPG and what the Department of Health (DH) could do.

The Minister outlined some of the work already undertaken by the DH:

- The Department has mapped the quality of bereavement care across the country. The Minister explained that the Freedom of Information request sent to NHS Trusts from Antoinette's office uncovered additional information that the mapping had not identified, so this has helped build a better picture of what the issues are.
- Sands are now commissioned by the DH to develop a clear map of where there are bereavement suites, where there could be improvements and what else could be done. The Minister explained that when the DH has a clear understanding of these issues, the Department can take forward the improvement work necessary.

The Minister outlined that next steps would likely include:

- creating a network and a proper training model for midwives and other staff involved in baby loss
- driving a far more integrated approach to bereavement care, which should emphasise that care should be suited to the individual needs of women and families.

The Minister said that he wants to get the systems in place in the next two years to help reduce stillbirths and infant deaths.

This work is being undertaken in the context of a DH programme designed to significantly cut neonatal deaths and stillbirth by 2020 [postscript: the targets are to reduce neonatal deaths and stillbirth by 20% by 2020 and by 50% by 2030, and can be found [here](#)]. By 2020 we want to be in the top five western countries for lowest levels of neonatal death and stillbirth, and the country in the world with the lowest levels by 2030.

The Minister said that his ambition is to get the NHS to the point where everyone working in maternity care feels part of a nationwide network of learning; where lessons from patient safety incidence and baby death are shared and incorporated within practice as a matter of course. This will be achieved through:

1. Broader changes being made to the NHS about making sure people feel free to speak up when things have gone wrong, and engage to learn from mistakes.
2. Standardised approach to make sure we get these things done
3. Change to how Trusts are incentivised to make sure that maternity services are improved and baby deaths are reduced.

Antoinette thanked the Minister for speaking with the Group.

At 17:47, the division bell rang, and the MPs attending left to vote. Antoinette nominated Francine Bates (CEO of the Lullaby Trust) to chair in her absence.

4. Bereavement care pathway

□ Update on project progress (Francine Bates, Lullaby Trust)

Francine Bates introduced herself and Drew Lindon, who manages the secretariat for the APPG on behalf of the Lullaby Trust.

Francine explained that in prior meetings of the APPG, the members agreed to work towards developing a bereavement care pathway for professionals which would cover the range of neonatal death, including early baby loss, stillbirth, and SIDS. Francine explained that at the last meeting, we had an offer from Rupal Kantaria, Chief Operating Officer of a strategic management consultancy firm to support the development process pro-bono, given that none of the charities present had sufficient funds or staff capacity to commit to this project. Unfortunately, the consultancy was subsequently unable to commit to this pro-bono support and this has led to a slight delay in kicking off the process.

Francine said that Antoinette had met with the Minister Ben Gummer MP in the week prior to today's meeting, along with a key policy official from DH's child health and maternity team and the CEO of Sands (who have been commissioned by the DH to carry out a separate project). Following that meeting, under the Minister's direction the DH has now committed a sum of money to support the development of a comprehensive bereavement care pathway. The charities Bliss, Miscarriage Association, ARC, Sands and the Lullaby Trust have agreed to collaborate on delivery. As such, Francine said that this project is going to happen, but not as soon as we had hoped at the time of the last APPG meeting. Francine said that the project will likely appoint a lead project manager to take the process forward, and her expectation was that once the arrangements with DH had been agreed, the next step would be to arrange a workshop for all interested parties to source ideas on scope, stakeholders and ongoing involvement.

Dr Nina Wilson asked why Petals had not been on the list of charities involved. Francine explained that she and the other charities (with the exception of Sands) had not been involved in Antoinette's meeting with the Minister. She said that the clear direction from the Minister and DH was that one organisation will need to be designated to receive and manage funding for the project. That charity has not yet been agreed, but once designated, that organisation would contract a project manager to lead this project, after which other charities will be invited to be engaged.

Nina said that Petals would want to be involved as their organisation is the only one which provides counseling to parents. Francine was clear that all organisations who were present (and probably other stakeholders too) will be invited to contribute their expertise to this project. She reiterated that one of the key barriers in setting up the project initially is that none of the organisations present have the capacity or funding to manage this project alone. Francine also drew a distinction between process and content. Content of the bereavement pathway will be subject to wide engagement but process of getting things off the ground was probably best left to one or two charities, especially those already in receipt of DH funds.

Dr Maya Al-Memar asked who would be appointed as project manager, and who will attend the workshop or workshops - just charities, or practitioners as well? Francine said the charities have only just this week heard that the DH will provide funding, so this has not yet been discussed. The charities can now 'put their heads together', but Francine

emphasised her view and that of the members of the APPG that we need wide input from all, including everyone who was in attendance today.

Jane Scott said that she felt that the person/appointee project-managing the bereavement care pathway development process should have relevant clinical expertise. She explained that bereavement midwives often need the clinical backing from above to "get new things done."

Nina requested that their organisations would like to be part of the organising group, and asked this to be minuted. Francine said that all those attending the APPG meetings would be invited to engage in this process.

Francine emphasised that in her understanding, the bereavement care pathway will be "owned" by the APPG itself although responsibility for delivering the project would be delegated to a group of charities who would ensure maximum engagement. She agreed that there needs to be a wide range of expertise, both charity and clinical, in developing the pathway. She emphasised that this will be a challenging process, as the pathway is aimed to talk about the whole range of baby loss, which require varying approaches. For example, the police have to be involved when a baby dies from SIDS, which is a different experience for parents than some other types of baby loss.

Sam Collinge asked whether we will be looking at standardising the role of the bereavement care midwife, as there is a lot of variety currently? Francine said this is the sort of discussion we should have in the workshop. Francine reemphasised that the process has not yet begun. These are issues to be discussed and decided by us all, but the pathway project will be DH funded and will have to agree a project plan with the charity in receipt of the funding. In addition, she said the funding has been offered thanks to APPG raising this directly with the Minister, so it is not for her to say or decide.

Amy Hawkes said that a dual specification for bereavement work is something that the DH is considering. Cheryl Titherly added that Sands have also been commissioned by NHS England to look at the role of the bereavement midwife.

At 18:05 Antoinette returned and resumed the Chair. Will Quince MP and Victoria Prentice MP rejoined the group shortly afterwards.

□ **Manchester example (Dr Alexander Heazell, Manchester University; Vicky Holmes, Bereavement Midwife)**

Dr Alexander (Alex) Heazell and Vicky Holmes introduced themselves, and their presentation slides will be shared along with these minutes. Dr Heazell explained that half of his time is devoted to developing research into stillbirth, and the other half is implementing good practice and supporting parents.

Alex said that while the Minister may want a single bereavement pathway, this may be difficult given the variety of circumstances this would be required to cover. The Stillbirth Integrated Care Pathway he and Vicky are presenting about today is broader than just stillbirth, but does not cover SIDS.

Alex said that "a maternity service should be judged on how it treats its most vulnerable clients." We need guidance as stillbirth affects mothers, families and wider society, yet

there are care quality issues and a wide variety of practice across the country. Standardising medical care is a means to reduce problems in future pregnancies.

Vicky explained that developing the guideline took three years, and involved a multidisciplinary team of professionals, charities, parents, and range of Trusts. The eventual pathway provided staff clear guidance on processes and roles.

Vicky said that there was a variety of evidence incorporated. That said, she emphasised that some of the key things that really make a difference to parents are fairly simple. For example, making sure the baby's name is included in the patient notes and used consistently is of great importance to parents.

In developing the pathway, they assessed the available evidence, and undertook a regional survey which asked NHS Trusts to rank elements of prior information offered through available clinical guidance. The guideline was then drafted and circulated for review. The researchers followed this review with a baseline audit before implementing the guideline, and are currently auditing again. Vicky and Alex emphasised that this is an ongoing, iterative process.

Moving from research to practice, the presenters highlighted that language is important throughout the process; this must be sensitive, accurate, and understood by the parents. To this end, the pathway document includes prompts for staff. Likewise, there is an emphasis on appropriately limiting the amount of information given to parents immediately after diagnosis, as parents are frequently overwhelmed by the gravity of this situation.

Alex explained that some controversial issues came up during the pathway development. For example, the group developing the pathway felt the existing guidance on seeing and holding the baby from the National Institute for Health and Care Excellence (NICE) and the Royal College of Obstetricians and Gynaecologists (RCOG) felt overly negative in saying professionals should not encourage parents to see or hold their baby. This did not "ring true" to the Pathway group and frontline professionals' experience.

Today, 11 NHS Trusts are involved in the pathway across the Greater Manchester, Lancashire and South Cumbria Strategic Clinical Network. The presenters explained that they offer an annual audit, and do site visits and training sessions.

Alex said the pathway seems to be making a difference to parents and staff. More information is being provided to parents, and there is increased use of better pain relief and examination. Alex said that while some of the participating Trusts are "still behind where we want to be", things are "going in the right direction."

Antoinette thanked both speakers, and invited questions from the attendees.

Jane Denton asked whether multiple births were included in the pathway. Alex said that their group are looking to expand into this topic.

Maya Al-Memar and Munira Ozra welcomed the work of the pathway group. Munira identified that the presenters had mentioned that the pathway principles are applied in other areas of loss too, such as early pregnancy loss, and asked them to expand on this point. Alex said they are running a perinatal group to which many professionals attend and share experiences and good practice.

Alex thanked the APPG for asking him and Vicky to present. He added that he felt that we are in agreement that to create a larger nationwide pathway, it is best to start with what has been done already (like this Stillbirth Pathway), and build from there.

Alex finished by saying that the idea of a single pathway document is very useful because you can teach more people in one go. But he made clear that “perfection should not be the enemy of the good”; Alex said we should use what we have to produce expectations of the service that should be delivered.

Antoinette said that this is what the APPG are trying to do with putting together the overall pathway. She thanked Alex and Vicky for coming along today, saying that this helps us take this agenda forward both medically and politically.

Northern Ireland example (tabled for information)

A separate model pathway used in Northern Ireland was sent to the group prior to the meeting for information.

5. Baby Loss Awareness Week 9th – 16th October

Speaker’s House event (Francine Bates, Lullaby Trust)

Francine updated the group on progress organising this event. This will be held as a lunchtime reception on Wednesday 12th October, immediately following Prime Minister's Questions. Will has booked this in the Speaker’s House. Francine said that a charitable trust set up by bereaved parents, Teddy’s Wish, working with Lullaby Trust and Sands has kindly agreed to sponsor the cost of refreshments. The apartments are free of charge, as they have been offered by the Speaker. The Group is aiming to use this as an opportunity to raise the issues around baby loss with their parliamentary colleagues.

The room has a capacity of 150, and the APPG will need to submit a list of external guests in advance. The Lullaby Trust is providing administrative support for the event, and will work with the APPG to source recommendations for guests. It was expected that at least half of the external guest list would include bereaved parents drawn from the charities.

Antoinette and Will said that they will looking to raise issues around baby loss in a backbench debate during or close to that week as well. Antoinette also requested the attendees to get in touch with their local newspapers in advance of Baby Loss Awareness Week to help promote issues more generally.

Remembrance event (Victoria Prentis MP)

Victoria Prentis MP outlined that APPG's plans to hold a remembrance event as well as the reception during Baby Loss Awareness Week, as discussed at prior meetings.

Victoria said that this event is still a work in progress. She explained that the parliamentary chaplain (Rose) is supportive of the event, but the APPG needs to obtain permission from the Office of Black Rod for external guests to attend. For the attendees' information, Victoria explained that Black Rod is a senior role who administers many aspects of Parliament, including some responsibilities for facilities.

Victoria said that the event will probably be held in the Crypt Chapel, which is just off Westminster Hall in Parliament, which holds about 150 people. She explained that the APPG would want to use this as an opportunity for people directly affected by baby loss in parliament.

In response to questions on how the guest list will be compiled, Victoria said that this was the APPG's 'first time', so they are currently considering the best course of action.

6. Infant cremations consultation response (Victoria Prentis MP)

Victoria Prentis MP reported back on the Ministry of Justice's (MOJ) published statement following their consultation on infant cremations. The APPG previously sent a response to this consultation which was acknowledged by Caroline Dinenage MP, Justice Minister.

Victoria said that the MOJ's response is a success for the group, and invited Catharine Gammie to elaborate. Catherine outlined that respondents to MOJ's consultation were broadly supportive of the proposals. Almost every recommendation the APPG made to the MOJ has been included. For example, parents will have more tangible ashes given to them, and the MOJ will be setting up a working party to look our (and others') proposals around fetuses under 24 weeks and report back by 2017. Victoria said that in the APPG's view, these are positive steps, and also help to bring our issues into mainstream cremation practice.

Victoria will push for the APPG to continue to be involved in this process and implementation of these changes.

7. Any other business

Will Quince MP offered to provide a tour of the Houses of Parliament after the next meeting, if we can book the next date for a Monday morning.

8. Close