ROSIE Maternity Voices
Working in partnership to improve maternity services

REPORT SUMMARY

Rosie Maternity Voices in partnership with Cambridgeshire SANDS

Special themed meeting on baby loss and bereavement care

held at Rosie Hospital, Cambridge on Tuesday 26th September 2017

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Background

Rosie Maternity Voices (RMV) is an independent, multi-disciplinary advisory and action forum led by service users. It exists to liaise, monitor, develop and improve maternity care for pregnant women and people, their partners and families who use the Rosie Hospital and its community services.

Rosie Maternity Voices replaced Cambridge Maternity Services Liaison Committee (MSLC) which ran from the 1990's until the summer of 2016 when its funding ended. RMV is funded with a grant from Addenbrooke's Charitable Trust (ACT).

At the first meeting of Rosie Maternity Voices in July 2017, parents from the newly formed Cambridgeshire SANDS support group requested a meeting looking specifically at parents' experiences of baby loss and bereavement care. The idea was fully supported by the Head of Midwifery and parent volunteers from both groups worked together to make the meeting happen.

Twenty-five people attended the meeting, with representation from service users (1/3 of attendees), Cambridgeshire SANDS, senior midwifery staff, consultant obstetrician, commissioning manager from Cambs & PB CCG, midwives (from Delivery Unit, LMW, Sara, Daphne, Clinic 21 & 24, Rosie Birth Centre, Community, Patient Engagement & Quality, Bereavement team, risk management), Petals Counselling Charity, Cambridge NCT, antenatal teachers, doulas and Healthwatch Cambs & PB.

Survey results

An online survey was open for two weeks prior to the meeting. It was shared by many of our partners, service users and on Facebook, with £20 spent on targeted advertising. 44 responses were collected in 14 days.

- 56.1% of responders had experienced a recent baby loss since 2015.
- 67.4% were 5 to 24 wks pregnant
- 25.6% were 25 to 42 wks pregnant
- 7% neonatal death.

We started by analysing the stillbirth and neonatal death responses, three recent experiences from 2016 and 2017 were read out in full. The rest of the results were collated by number of mentions:

What was GOOD?	**What was NOT SO GOOD?**
Midwife - mentioned 16 times Staff/everyone - 14 Doctors - 2 Sonographer, Maternity Support workers, NICU, EPU, Anesthetist - 1 Petals service - 4	Being on Labour or PN ward - 7 Refused or delayed early scan - 6 Insensitive comment - 6 Doctors - 5 Follow up care - 4 Lack of info - 4
What like to see IMPROVED?	**OTHER COMMENTS?**
Different waiting room/scan room/ward - 8 Follow up care - 5 More info/leaflets – 5 Referral to Petals - 3 Empathy - 3	A film crew in Clinic 23 Lack of knowledge about molar pregnancies Subsequent pregnancy notes said 'not given birth before' Prolonged wait from miscarriage symptoms to actual miscarriage

Parents' experiences

The parents who talked at the meeting have written a brief summary about their baby's death:

Kym's son Alfie Field died at the trust on 20th December 2015 age 36 hours old. He sustained a severe brain injury during the last 3 hours of labour after a catalogue of errors. The main one being that staff misinterpreted his CTG trace.

Rebecca's son Bean was stillborn in August 2016, after attending the Rosie because of concerns about reduced fetal movements. Induction was started and Rebecca returned to the Rosie about 36 hours later to give birth to Bean on a Sunday. Although staff were caring, there were no offers of support such as cuddle cot, memory boxes or support from a specialist bereavement midwife. A post-mortem did not identify a cause of death.

Alyx's daughter Skye was stillborn on 3 February 2017 at full term due to a triple nuchal cord. Alyx had been into the hospital a few days prior with reduced movement although the staff did not detect any fetal distress on that occasion. When reduced movement was noticed three days later, no heartbeat could be found. Alyx was then induced and had a natural birth on the Delivery Unit.

Danni's 3rd daughter Bethan was born at the Rosie in 2015. She was 37+3 weeks gestation and died due to stillbirth. Danni had an elective caesarean section, subsequently finding out that Bethan had Down's syndrome. Her experience on the whole was very positive, largely due to the incredible consultant she happened to be in the care of. Danni found the bereavement team to be very organised and helpful and the midwives who cared for her and her husband did so with careful detail and thought.

Karen and Russell's son, Charlie, was born by induction on the labour ward on the 9th March 2014 at 21 weeks. The pregnancy had had a routine 12-week scan and on returning for the 20 week scan a diagnosis of renal agenesis was identified by the sonographer and confirmed by a senior one, there was little compassion from staff in this department. The care by midwives was fantastic and Charlie was treated with respect and dignity. The main concerns arose from a subsequent pregnancy where the hospital staff were unaware of the history and could have done a better job to appreciate the anxiety associated with the birth. The care in the Lady Mary Ward after Jasper was born was poor and a better understanding of both parents' mental wellbeing could have supported breast feeding and early care for their second son. [Karen was unable to attend the meeting due to illness, Russell wrote about their experiences and it was read out at the meeting.]

Themes and feedback

Here are some of the memorable themes and feedback which came through from the parents' experiences in the meeting and from the online survey results.

All staff

Staff may not realise what an impact they are having on bereaved parents lives i.e. parents will feel a deep connection to them, remember them and their behaviour forever. This applies to ALL staff including doctors, midwives, maternity support workers, clerical, etc.

"Greater empathy that although staff may see this every day, for parents it's possibly the worst day ever."

Parents reported a sense of deep fear about seeing their deceased baby, as often they haven't seen a deceased body before, and have no idea what it will be like. Staff could support parents in this by preparing them for what their baby may look like when born.

For all new midwife employees and in time existing employees of the Rosie unit to be trained to deal with the trauma of stillbirth.

An induction process put in place so that everyone is competent in this area in providing immediate care for the family.

For rainbow (subsequent) pregnancies to be acknowledged by staff. Stickers on the clinical notes/computer notes to flag up that this is a sensitive subject surrounded by huge worry and anxiety, and that they should adapt the care and conversation accordingly.

Doctors

The parents talked about a general sense of most doctors not having any bedside manner/empathy in this situation. Saying a quick and cold 'sorry for your loss' wasn't enough when it comes to what bereaved parents really need. One parent talked about the doctor giving a graphic, frightening description of post-mortems which scared the parents so much they declined a post-mortem. Later there was a sense of regret felt that they would never know what happened to their baby. A better way would be to talk about it from the parents' perspective, and with understanding and compassion that the parents are experiencing a traumatic loss.

In the survey, doctors were mentioned twice in the 'good' and five times in the 'not so good'.

Midwives & Rosie Bereavement Service

Midwives made a real difference to bereaved parents, with 16 mentions of midwives in the 'what was good about your care' survey question.

The Rosie Bereavement Service is highly thought of and well loved.

"On finding out our diagnosis, we were asked if we wanted to see the bereavement midwife which we declined, in hindsight I think it should automatically just be part of the process, as once we met her she was a wonderful support."

Parents whose baby had died in utero were immediately referred and talked of the excellent care they received from the specialist midwives, including gentle care during labour, memory boxes, advocacy and information which continued after leaving hospital.

However, bereavement services do appear to be reduced or not available at weekends, which is detrimental to parents who are at the Rosie at this time.

To help to build a positive relationship again with the hospital after such a traumatic event, bereavement midwives could offer support for mothers during rainbow (subsequent) pregnancies - phone calls to offer support, a listening ear, attending scans/appt if required to assist these mothers through an incredibly anxious, worrying and frightening time.

Petals counselling charity

Petals also came up a lot in the meeting and survey as being a lifeline for bereaved parents.

Karen Burgess, CEO from Petals talked about the psychological impact of baby loss. How as a society we are okay with grief: crying, sadness, guilt, etc. However, baby loss parents are also coping with trauma, and that is very different to grief. Unresolved, it can distort our perception and identity and damage relationships. Grief and/or trauma left unresolved can result in mental health issues and a diminished life experience.

Here's are some of the examples of trauma language which came through in the parents' stories…

"When we were told I didn't believe it, I kept saying "It's not true!""

"Staff need to know what was said to me, positive or negative; body language; the room; everything mattered. It stays with you forever."

All the parents used the words *"I felt terrified,"* at some point.

Communication

The parents whose baby died at 21wks gestation in the March received a letter about the Tour de France coming to Cambridge in June and warning of road closures around his due date to allow more time getting to hospital in labour.

Filming in Clinic 23 was raised in the online survey and it was confirmed that Channel 4 are filming a documentary about stillbirth and difficult pregnancy outcomes. There are posters displayed in the clinic about it. Filming is rolling in the consultation room all the time so parents have to opt-out and footage is then deleted without being viewed. There was a discussion about this, one bereaved parent did participate in the documentary and found it a good experience but there were concerns from others about the privacy of parents at a vulnerable and traumatic time.

NICU

The parent whose baby died at 36 hours old in NICU over a weekend missed out on the Rosie Bereavement Service care and NICUs Footprints Service. She talked of them feeling totally alone, no information about cuddle cots, memory boxes, a post mortem, coroner, funeral, Petals or SANDS. On the postnatal ward they felt terrified of leaving the room and didn't eat for three days. A family member had to come in and advocate for them.

Sonography/scanning

There was a lot of feedback in the survey about scans, particularly with early baby loss. Having a different waiting room and scanning room was mentioned eight times in the survey in response to the 'improvement' question and being refused or delaying an early scan was mentioned six times in 'not so good'.

It was also highlighted in the parents' experience of pregnancy after baby loss. Sonographers were not aware of the previous history. There were difficulties booking a 16-week specialist scan in Clinic 23 and a partner having to come in to the hospital and visit the consultant's PA in person to resolve it.

Subsequent appointments and pregnancies

The same parent talked strongly about how a lack of care on Lady Mary ward after the birth of their 2nd baby was a "massive contributing factor" to breastfeeding ending and post-natal depression. Following the birth, late at night the partner was told to leave, the mother was really poorly and laid awake all night terrified her baby was going to die. He recommends a greater understanding of the mental health of a bereaved mother having just given birth and left with no support overnight.

This mother had to wait in the waiting room full of heavily pregnant women for postnatal checks and appreciating how this can induce severe anxiety and/or panic attack.

Ideas for improvements, by impact/cost matrix

Working in groups, with a bereaved parent represented in each group, participants came up with the following ideas for improvements, arranged here in an impact/cost matrix:

High impact	Parents will never forget you *"Make me feel like a mum, say my baby's name."* *"Sit on my bed and talk to me."* *"Hold my hand."* *"Please walk us to our car, we're leaving hospital without our baby."* Buddy staff with senior staff to improve communications. Give information about Doula UK Access Fund specialising in stillbirth Communal areas in postnatal wards are terrifying, please bring us food. Stickers or marker on maternity notes and electronic files for subsequent appointments and pregnancies (so all staff are aware including clinic receptionists) Ensure bereavement team involved very early on, regardless of where in the hospital baby dies. Parents given a personal contact in PALS team. Communicate back to parents what has been learnt, changed or improved from their baby's death.	Provide quiet rooms for scanning, breaking the news and waiting rooms Provide a soundproofed room for giving birth to a stillborn baby or bereavement suite Provide a room away from postnatal ward Make sure parents whose baby dies in NICU get the same standard of bereavement care, over weekends too. Flag up baby loss in EPIC Mandatory bereavement training for all staff (MDT) incl. understanding trauma

	NICU staff to attend meetings.	
Low impact	Zero-low cost	High cost

Feedback from the meeting

"Brilliant meeting and some very brave mums. This is what these [Rosie Maternity Voices] meetings should be all about; my midwives came out buzzing too and we talked about it at just 5. Huge well done." Anna Shasha, Head of Midwifery

"It was a very moving meeting, well done." Julie Taylor-Robertson, Community and Rosie Birth Centre Lead Midwife

"From Addenbrooke's Charitable Trust's perspective I'd very much like to be able to do what we can. Two of those areas that I'm already looking at is to improve the seating area outside the delivery unit bereavement room and looking at some environmental improvements to the Jane Thorley Counselling Suite. It's interesting to learn of the disparity between weekday and weekend bereavement care and the recommendation of further training for staff. I'd be keen to look at how the charity can support the hospital and patients in both of these areas." Alex Cavanagh, Head of Business Development, Addenbrooke's Charitable Trust (ACT)

"Thanks for sharing this [survey results], it seems that for the most part that we get this right, but there are aspects that we need improve. Definitely thought provoking with regard to staff empathy." Jeremy Brockelsby, Consultant in Feto Maternal Medicine, Clinical Director Women's Services

Later update from Cambridgeshire SANDS

SANDS have just released a National Care Pathway. This has been published to eleven hospitals to help them guarantee an excellent standard of care by following the documentation provided and training the health care professionals across these sites. In 2018 another batch of hospitals will be chosen before finally rolling it out nationally. This is really exciting positive news and we hope the Rosie hospital use this resource in making the care they offer consistently excellent for all families affected.

Actions & outcomes

- ✓ All the bereaved parents will be invited by the Head of Midwifery to participate in the #WhoseShoes event on Friday 24th November 2017. Action: Anna Shasha, HoM
- ✓ For all departments to be sent a copy of this report summary and survey results, look at the ideas for improvements and take action on the 'quick wins' (high impact, zero-low cost). Action: all Trust meeting attendees
- ✓ ACT is working on improving the seating area outside the delivery unit bereavement rooms and looking at some light-touch improvements to the Jane Thorley Counselling Suite. Action: Alex Cavanagh, Addenbrooke's Charitable Trust (ACT)

- ✓ Cambridgeshire SANDS are working with the Rosie to help it improve bereavement care generally, the long-term goal is to open a more substantial bereavement suite than rooms 1 and 2 the trust currently use. Action: Kym & Rebecca
- ✓ With their permission, Karen & Russell's story will be read out at the next Sonography/scanning team meeting and action taken. Action Ellen Dyer, service user & sonographer
- ✓ For the Local Maternity System (LMS) stillbirth, neonatal and Serious Incident work streams to receive a copy of this summary report. Action: Liz Phillips, Commissioning Manager, Cambs & PB CCG
- ✓ For Karen Burgess, CEO of Petals Counselling Charity to be introduced to the Chair of the LMS perinatal mental health work stream and invited to participate. Action: Liz Phillips, Commissioning Manager, Cambs & PB CCG

Please report back any progress to rosiematernityvoices@gmail.com for the 11th January 2018 Rosie Maternity Voices meeting.

Learning Outcomes for Rosie Maternity Voices

This meeting was RMV's first themed meeting, here are the learning outcomes captured for the planning and delivery of future themed meetings:

- Engage at an early stage in the planning with specialist trust staff and charity, voluntary and community partners to co-design the meeting together.
- Ask parents if they would consent to their stories being videoed at the meeting so more staff are able to watch their powerful stories and parents are not being asked to relive their experiences over and over at other meetings.
- Don't try to pack too much in the agenda. Allow more time for co-production and co-design, to flesh out some of the ideas further into projects with actions and named people responsible.
- Take a vote on which ideas or projects should be prioritised and discuss potential funding streams.

This summary report was written by Rosie Maternity Voices, Cambridgeshire SANDS and all the bereaved parents involved in the meeting.

For a copy of the survey results, please contact rosiematernityvoices@gmail.com

Final version: 17th December 2017
Circulated to RMV core and associate members: 17th December 2017