# Worthing Bereavement & Loss Listening Event

Partnered with OSCAR'S Wish Foundation

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Maternity and Neonatal Voices Partnership
Working in Partnership to Improve Maternity & Neonatal Services

We hosted a listening event to hear the voices of parents that have experienced baby loss, bereavement and TFMR. As this was the first time the MNVP have hosted this type of event, we discussed with some families (with lived experience of loss & bereavement) and worked with Oscar's Wish Foundation & a grief counsellor to come up with a format that would work for the families attending.

**Things that we agreed were important for the listening event;**

- Psychological safety when sharing their feedback.
- An open, safe space for families to tell us their story in as much or as little detail as they felt comfortable with.
- A neutral location, easily accessible by car and public transport for service users. (ie not in a hospital or maternity setting)
- Tea, cake and an informal, supportive atmosphere.
- Colouring, fidget and grounding toys.
- Access to support from grief counsellor throughout the listening event for a debrief and de-escalation.
- Service users encouraged to take breaks and ask for support if needed.
- 1 to 1 listening slots with dedicated impartial listener, this was with MNVP leads or Public Involvement team leads (service users felt that it would be too difficult or triggering to share with maternity or bereavement staff that were involved in their care).
- Ahead of the event we let families know what to expect on the day and how we would move forward with their feedback following the event (with their permission).

**Following the event;**

- A one off follow-up with grief counsellor after the event.
- Onward signposting & support shared with service users.
- Their stories written up and shared with service users' (if they wanted them).
- A detailed thematic report with anonymous case studies created (to protect the anonymity of the service users involved).
- A report with the high level themes shared with service users that includes the areas for improvement.

Nine families kindly shared their in-depth experiences of their pregnancy, loss and bereavement experience whilst receiving perinatal care form University Hospitals Sussex at some time over the last 8 years. We are very grateful to these families for taking the time to share their experiences with us, to help improve future care for families.

The families that we spoke to would like to remain anonymous, so for the privacy of these families, we have used a case study and thematic analysis approach for this report rather than providing full details of these experiences. These experiences span across multiple areas of care including home, MAU, antenatal, postnatal & labour wards, bereavement suites, EPU and termination clinics.

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# What went well for service users

Access to the bereavement suite was found to be very helpful

Families were supported to make memories with their baby, these mementos are cherished

EPU staff were friendly & supportive

Service users recalled being supported with kindness & compassion

Families were able to spend as long as they needed with their baby, this was vital for them

Some service users reported that midwives & consultants took time to explain what had happened & what was next

Some sonography & screening staff were kind and supportive

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# Improvement opportunities

## The stories we heard identified the need for...

- Consistent bereavement care offering, including information on what to expect & how to get the support they need. This should include follow-up's and reaching out more than once.
- Cross service & multi-disciplinary team approach to care.
- Service user's concerns listened to & taken seriously.
- Triage line encouraging service users to come in for further investigations where appropriate.
- Induction of labour & mode of birth being personalised and clearly explained to enable personalised choice.
- Adequate pain relief when labouring/delivering.
- Sensitive, trauma informed, non-minimizing communication.
- Clarity on the care of the baby after the loss
- Additional Staff bereavement training.
- Transparent and timely communication from maternity & neonatal teams.
- More support and information for fathers & non-birthing parents.
- Bereavement care being provided away from maternity units.
- Robust high risk and recurrent loss care pathways.
- Information & aftercare/support for miscarriage.

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# Since the event we have...

- Written up each experience in detail & used this to create a case study style report with themes for analysis. This has been given to the directors of maternity, gynaecology & neonatal services.
- Shared the stories with the service users who came to the listening event (if they wanted them).
- Identified shared themes to take forward, as well as improvements opportunities within each experience.

# Next steps...

- Deep dive review meeting planned for October, this will include key stakeholders and service users.
- Complete a full review of the bereavement & loss service.
- Actions co-produced with service users & taken forward in a Trust led workstream via the Maternity Improvement Group.
- MNVP plans for additional bereavement & loss listening event in 2025/26.
- MNVP business as usual to listen to and hear voices of bereaved parents. This to include 1 to 1 discussions as needed.