

Infant Loss Report

2026

REPORT BY



together we
Cumbria

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Executive Summary

This project was commissioned by Carlisle & Eden and West Cumbria MNVP and used NHS England Additional MNVP Funding monies 2025/2026.

During this project we were able to listen to the experiences and thoughts of families and professionals in North Cumbria around pregnancy loss, particularly focusing on the support they received with a view to finding out what good support can look like. We are very grateful to all those who shared their experiences and insights into times and experiences that are deeply distressing.

Insights were gained from questionnaires, focus groups and informal community listening.

Families shared experiences of their care and highlighted instances of compassionate trauma informed care with clear communication and meaningful emotional support that was not time bound. However, almost equal amounts shared deeply distressing experiences in terms of physical and emotional care. They highlighted overwhelming clinical language and lack of ongoing support. All of these interactions, both positive and negative, have a profound impact on families memories and recovery.

Professionals highlighted similar concerns, in particular around language, training needs, inconsistency of care and support depending on gestation and area of NHS accessed and general system pressure.

With regard to what compassionate care around loss should look like, there was significant attunement between professionals and families. The shared insights are captured here along with recommendations around improving emotional aftercare, communication, consistency and continuity of care.

Background & Project Context

As part of wider system work on early infant loss it was identified that more listening from service users and professionals was needed. It had already been identified that support for families varied by gestation and location.

We had already heard that during their grief it was difficult for families, who often felt the need to advocate for their care but due to their understandable distress, this was difficult/impossible to do.

Additionally, subsequent pregnancies were understandably times of significant anxiety and families were reporting varying levels of clinical and emotional support in this time.

The project aimed to:

- Hear experiences across all loss pathways
- Understand what care/support means to them
- Hear professionals perspectives
- Identify barriers
- Co-develop, with all stakeholders, recommendations for change

We were able to hear from:

- Bereaved parents
- Pregnant families
- Midwives, including specialist midwives
- A & E staff
- Staff from Obstetrics and Gynaecology including specialist staff
- Neonatal professionals
- Hospice teams
- Voluntary sector partners
- Peer support providers

Methodology

We used a multi-method approach and ensured that this was trauma-informed in all aspects and as accessible to as many families as possible. Signposting was offered to additional support to ensure safety.

Methods:

- Questionnaires for services users and professionals.
- Focus groups online and in person.
- One to one sessions online and in person.
- A themed review of data captured.
- Our specialist practitioner within the service was also able to use their own experience of supporting multiple families in a range of settings to explore and inform the themes gathered when reviewing the data gathered.

Limitations identified:

Difficulty engaging families and professions with a subject that can be deeply distressing and personal. The short-term nature of the project and the seasonal timing also impacted the work.



Participant Profile & Demographics

We were able to capture the voice of those who have experienced loss from 4 weeks gestation through to neonatal loss. We also spoke to families who had had subsequent pregnancies and also heard from professionals supporting families across this range.

Responses:

- 19 individual service user replies to questionnaire.
- 9 individual responses to questionnaire for professionals.
- 2 one to one conversations with service users
- 2 one to one conversations with professionals
- 1 focus group with 3 professionals
- 1 focus group with 2 professionals
- 1 focus group with 5 service users



Responses were from those who accessed/worked at a number of settings:

- Cumberland Infirmary Carlisle
- West Cumberland Hospital
- Newcastle RVI
- Wrexham Maelor
- Home-based care

Demographic information was obtained from service users responding to questionnaires.

Ages ranged from 20–24 through to 45+, representing a diverse cohort.

Most service users did not identify themselves as disabled and those that did stated they identified both physical and mental health disabilities.

Losses were reported across a wide time range from 2007 onwards, with most being recent (2023–2025).

Postcodes captured showed wide representation across Carlisle, West Cumbria, rural localities and bordering regions.

Professional responses were captured from staff/volunteers within maternity, EPU, A&E, neonatal, hospice, counselling, voluntary sector and peer support roles.

All services users identified as White British.

Cross-Analysis of Themes

There was strong alignment between families and professionals:

- Both highlighted the importance of communication and jargon.
- Both noted inconsistent information sharing.
- Both emphasised the need for continuity and follow up.
- Both noted environmental issues, especially in A&E.
- Both described inconsistency in aftercare.

For families the emotional impact on them was the focus of responses.
For professionals the system constraints were the focus of their responses.

The shared “dream service” (see page 16) across groups strengthens confidence in the recommendations. Addressing the common themes raised by staff, and service users would deliver a strengthened more consistent service and experience of loss across the services providing care to parents experiencing loss.

SERVICE USERS	PROFESSIONALS
Language/terminology/compassion/trauma informed care (negative and positive)	Language/terminology/compassion/trauma informed care (negative and positive)
Information and signposting	Information and Signposting
Ongoing support (longevity)	Continuity of care/ownership/responsibility
Limitations within the NHS	Limitations within the NHS
Subsequent pregnancy	Staff training and support
Environment	Environment
	Staff as intermediary

Attunement between Service Users and Professionals

There was significant alignment between professionals and staff in many areas. This matches with research by Lee et al., 2023 who noted a 'broad overlap in the needs identified by bereaved parents and their health care providers as well as general agreement regarding the barriers to providing effective care' (p.52)

PROFESSIONAL

Described how important it is that professionals acknowledge the baby in the room.

SERVICE USER

Described how important it is that their baby is recognised, that they existed, if only for a short period.

FINDINGS: SERVICE USER EXPERIENCES

Overall half of respondents (service users) report excellent care and compassion from professionals whilst half say their experience was the opposite.

Where it is reported that care has not been supportive, this has been due to;

- Language
- Being treated as a medical procedure
- Feeling unheard
- Not receiving long term support
- Not being signposted to support
- Delays in medical support

"When midwives made time for me like any other mum."

Communication & Language

The words used can have a profound impact for families. During this time of great distress kind, compassionate and thoughtful language as well as thoughtless language can all have a profound and lasting impact.

Service users who had experienced loss many years ago were able to easily recall significant conversations. Distress was reported around the thoughtless use of medical jargon in particular. Whilst compassionate conversations were deeply felt and supportive.

Many service users find it helpful and place a lot of importance on what they are told by a Doctor and seek this out.

Consultant saying "it's a positive that shows I could get pregnant and that the best time to get pregnant again is the next month. I felt so dismissed in that moment."

Other unhelpful comments:

- *"Miscarriage is just like a bad period."*
- *"Maybe its for the best, it probably had something wrong with it, at least you weren't far along."*
- *In relation to an early loss, being told to "go to the toilet and then don't look and just flush it away."*
- *"Oh well, if you have 3 children already it's probably best that you don't have a fourth."*



Information & Signposting

Most report that they were unprepared for what they might experience during a loss, it's not something anyone ever expects to experience. They did not know what to expect physically or emotionally. They do not always feel that information is conveyed adequately.

They do not feel that they are adequately signposted to support such as peer support, information about physical processes, mental health resources or to remembrance services.

Emotional Support

Families often received excellent clinical care but limited emotional aftercare. Whilst some reported that they felt forgotten, others reported ongoing support from staff that was deeply impactful in their grief journey.

Environment

The difficulties of the physical environment within NHS settings is a known and ongoing issue, with services users reporting the distress of receiving the 'worst news' in rooms where others are receiving the 'best news'.

The need for a suitable dedicated space for those experiencing loss is mentioned by most professionals and service users.

Patients being cared for on a surgical ward is less than ideal. There is recognition of the need for dedicated space. in many aspects of mat/gynae care.

Continuity of Care

It was helpful to have a named contact particularly during subsequent pregnancies. Ongoing contact from staff is greatly valued and appreciated.

Specialist staff provide a wide range of non time limited support with practical issues and this is greatly appreciated.

The organising of funerals is mentioned in particular. Currently organising this in West Cumbria is particularly challenging for staff due to the lack of a contracted funeral director. This is a shame given how much this support is valued.

Care such as additional scans or referral to Maternal Mental Health are greatly appreciated. This is mentioned by service users and professionals.

The care in subsequent pregnancy is largely really appreciated although can be inconsistent, one service user reported difficulty in having early scans despite these being promised, they were eventually organised after contacting staff repeatedly. Others do not remember getting additional scans.

Subsequent Pregnancy

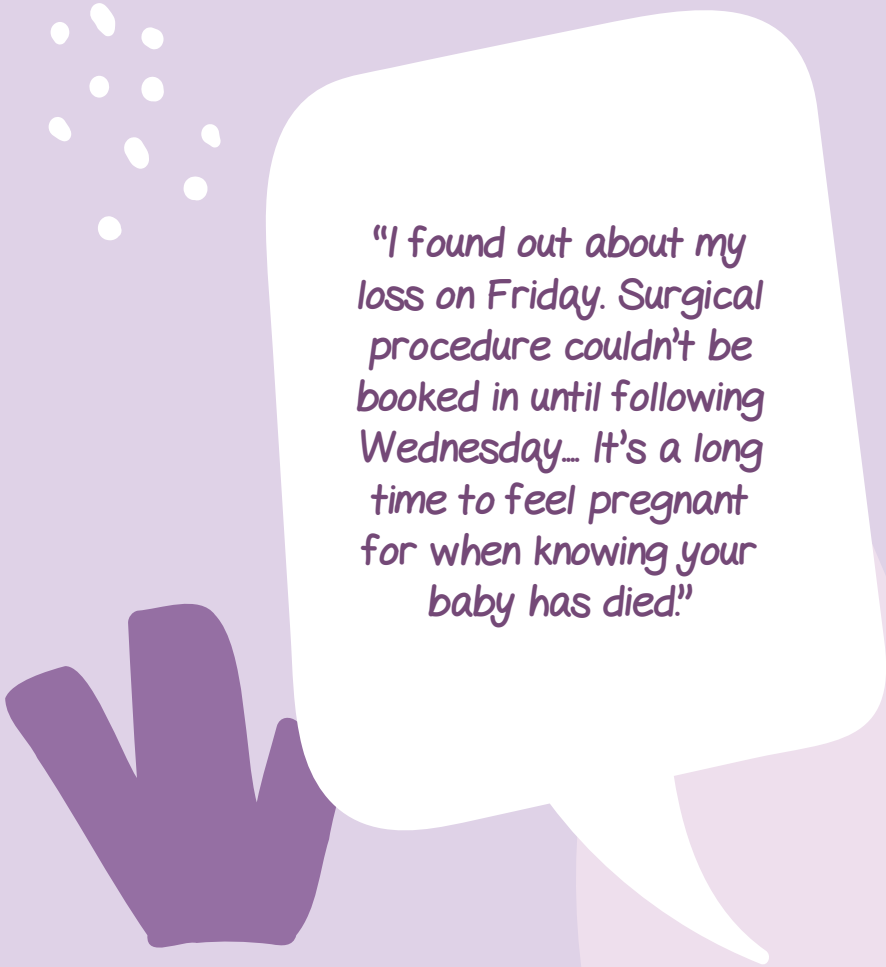
Understandably, this can be a time of significant anxiety and families reported that they found it helpful to have additional scans, although these were not consistently offered/available.

Having a point of contact for subsequent pregnancy is appreciated. Links with a named member of staff they have had an important relationship with are really meaningful. This is challenging within the NHS and a small service/team.

Follow up care and support is mentioned by services users and professionals. Service users mention the lack of ongoing support in particular mental health support.

System Challenges

Delays in care were often reported, with this causing significant distress.



"I found out about my loss on Friday. Surgical procedure couldn't be booked in until following Wednesday... It's a long time to feel pregnant for when knowing your baby has died."

FINDINGS: PROFESSIONAL PERSPECTIVES

System pressure

Professionals described:

- Staff shortages
- Lack of consultant led clinics
- Lack of 24/7 services/clinics
- Delays in postmortem results
- Lack of ownership/continuity of care
- Staff often work additional hours, swap shifts, come in on days off to provide supportive care.



Language, Empathy & Rapport

Professionals are acutely aware of the impact of language on families. They are also aware that perhaps due to a focus on medical care (making patients safe) language used by some professionals is not sensitive or empathetic.

It is acknowledged that it is particularly difficult to convey information in times of grief and staff who responded to this project described how they seek to overcome this difficulty with care and compassion, particularly where they were able to rely on specialised skills/knowledge.

Staff note the value families place on feedback from Doctors and that whilst some Doctors are excellent at this, information is not always understood by families with staff such as midwives/nurses then needing to act as an intermediary to ensure families are supported.

In discussions about what we mean by support, and how rapport is built, there was a general feeling that this is an innate ability, you either have it or you don't and there were some lovely discussions about the ways staff do this. Staff aim to find out 'What does the person need from you'.

They will tell people that this is their specialist role to gain trust and find it valuable to have this specialist knowledge in this context.

Professionals believe that there is a lack of ownership regarding care especially RE early loss. They state that someone needs to *'be that person'*.

Staff express concern about how people are managing at home and whether they are getting the support they need. One expressed that if they were admitted it might feel like something is being done which could be helpful for families.



"I was home alone when I passed my baby. Felt alone, no one to talk to about it.... It absolutely broke me."

Information Sharing

Whilst staff report that they are confident in knowing what information would be helpful for services users and that they always share this, those supporting families do continue to hear that they aren't getting this information.

For example; information about local peer support group (Silent Footprints/Team Evie), information about the regular service at the crematorium.

Support for Staff

Those who participated were clearly compassionate and supportive in their care of families, and they are dedicated to doing this in their role. However, it can understandably be distressing. There is no formalised support for staff who report chatting to colleagues on an as and when basis, some expressed that they would like more formal arrangements to be put in place.

Staff approach their role very much from a being 'with women'. They very much feel they are there to be there for the women although they do notice the impact on their wellbeing.

Staff report swapping days or working extra hours or working on day off to provide support.

Environment

Professionals also expressed dissatisfaction with the physical layout/facilities of care, additionally highlighting artwork on walls that is inconsiderate of those experiencing loss.

One member of staff talked about the long walk through to the room at the end of the corridor past rooms with people with living babies and with walls full of positive affirmations such as *'this is the day we have been waiting for'* and that these are inappropriate and should be removed.

Training

Whilst there is now some mandatory training in place, this is shorter than staff would like and not across the board for any professional who may have to support families with loss. Specialist staff have delivered training to colleagues that has been eagerly and well received. There is a desire amongst staff for longer, mandatory training and the time to attend and deliver this.

A number of staff have attended additional training. There is no mandatory training except as part of professional standards sessions.

Specialist staff have delivered training to colleagues and this has been eagerly and well received. Staff are very committed to continuing to provide this training, they particularly mentioned opportunities to provide longer training sessions rather than shorter sessions.

Findings Across Gestation

Most respondents reported positive and challenging experiences within the same journey. Positive experiences (particularly in losses over 24 weeks) were often linked to compassionate care whilst negative experiences tended to relate to system challenges such as delays in access to scans.

COMMON THEMES UP TO 12 WEEKS

POSITIVE:

- Caring staff
- Peer support
- Access to EPU

NEGATIVE:

- Lack of information
- Dismissive language
- Long waits

COMMON THEMES BETWEEN 12-23 WEEKS

POSITIVE:

- Memory boxes
- Remembrance services
- Follow-up appointments

NEGATIVE:

- Inappropriate environment (e.g. A & E, corridors)
- Unhelpful medical jargon
- Lack of clarification of information
- Lack of time to process information

COMMON THEMES 24 WEEKS +

POSITIVE:

- Caring staff
- Funeral services

NEGATIVE:

- Inappropriate environment
- Abrupt / blunt language by consultant



The DREAM Service

The following suggestions for the ideal service are drawn from all the interactions during the course of the project. In discussions, participants were asked to think of what should be in the service in an 'ideal world'. These also became a source for the recommendations overleaf.



Recommendations

The following are suggested for further consideration. In terms of prioritisation there is already work being undertaken on physical environment that will address the concerns expressed by respondents.

Other recommendations rely on wider system change, particularly staffing and it is appreciated this may be a longer-term priority.

STAFF TRAINING

Mandatory, regular, dedicated rolling training sessions are recommended for all staff who may support patients experiencing loss at any gestation. These should allow sufficient time to focus on a trauma informed, compassionate approach and be an opportunity for information sharing, sharing of good practice, reflection and learning. Where possible the voices of 'experts by experience' should be included in delivery.

COMMUNICATION

Given that language and compassionate care is a focus of all responses it is recommended that wider staff training on this be considered as a priority.

INFORMATION

Standardised information packs across all gestations to be accessible across all relevant service, to reflect the impact on loss on families regardless of gestation. This should be supported with repeated verbal communication and visible signposting.

ENVIRONMENT

Dedicated private spaces with a mindful approach to the service user experience in attending these (e.g. signage and artwork).

INCREASED ACCESS TO APPROPRIATE SERVICES

Less reliance on A&E with specialist services available 24/7, led by Consultants to ensure access to all aspects of care.

STRUCTURED LONG TERM SUPPORT

Pathway for follow up care to include; guidance on lactation suppression, funerals, memory making, mental health support and peer support.

SUBSEQUENT PREGNANCY

Rainbow clinic with a named contact and access to additional scans and appropriate tests.

PROFESSIONAL SUPPORT

Consider implementing and supporting access to regular reflective support, formalised/gathered together and so this would be suggested as the next priority.

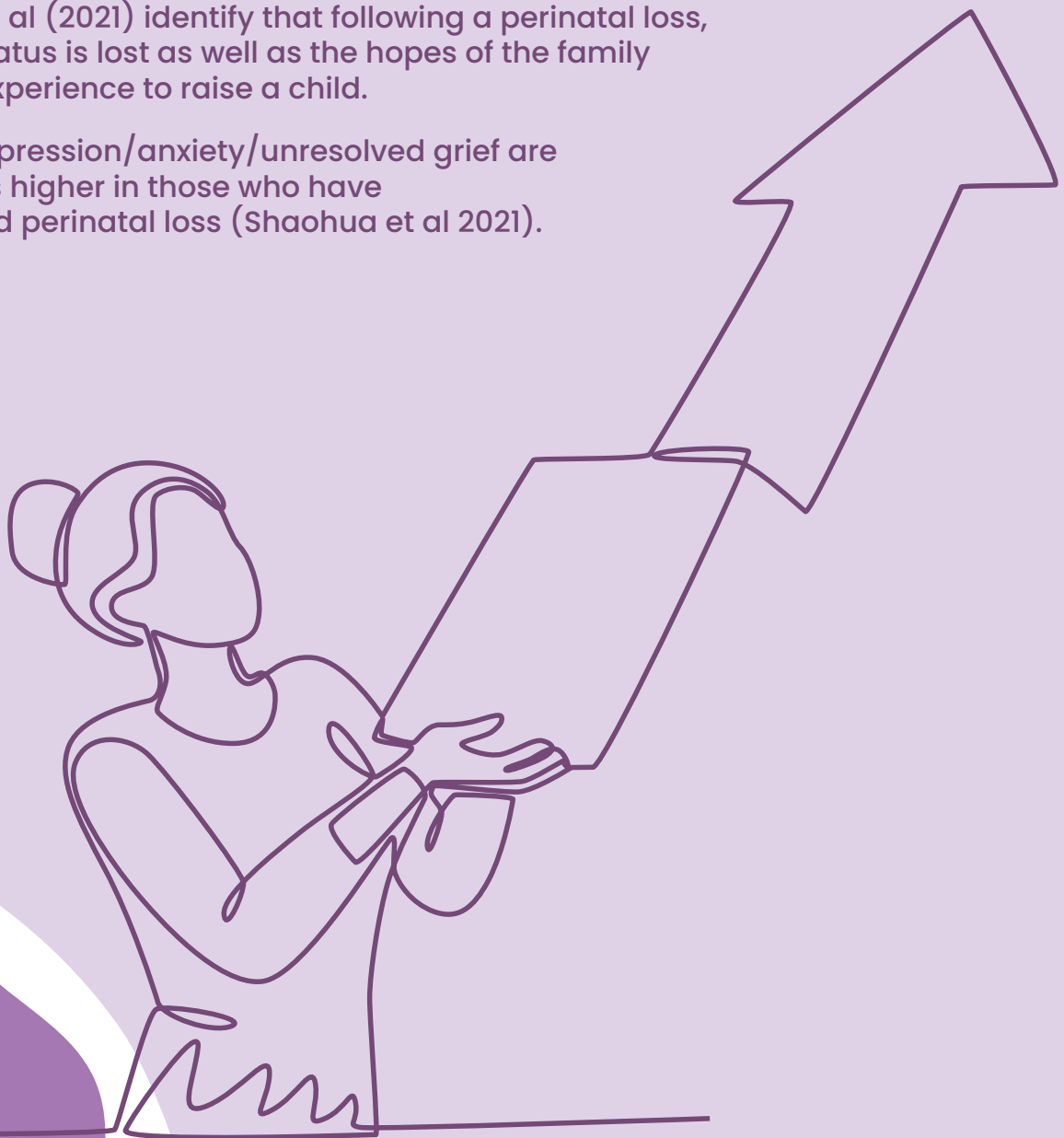
Why it's important to keep improving

Evidence shows that when women feel satisfied with care during/ following a loss, they are less likely to experience depression, anxiety or unresolved grief. (Lee et al 2023)

In their study of parents experiencing loss between 20–24 weeks Smith et al (2020) reported that families found the use of the term 'miscarriage' inappropriate and detrimental to their recovery. Additionally for some, the term 'miscarriage' did not prepare them adequately for the physical process of a loss at this stage. The terminology 'miscarriage' also increased mothers feelings of being at fault.

Shaohua et al (2021) identify that following a perinatal loss, parental status is lost as well as the hopes of the family and their experience to raise a child.

Rates of depression/anxiety/unresolved grief are reported as higher in those who have experienced perinatal loss (Shaohua et al 2021).



Conclusion

The responses and information we have heard show a strong and reassuring alignment between families and professionals around what trauma informed compassionate bereavement care should look like. There are systemic pressures that affect the ability to provide the service that all would desire.

The insights gathered provide useful information to facilitate a shared vision for a bereavement care pathway that is compassionate and supportive for families.





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