Appendix 1: Supporting families and staff

A compassionate, trauma-informed framework

The death of a baby is deeply painful and distressing for families. This distress is felt across the whole system by clinicians, teams and organisations. Additionally, in a clinical setting, the subject of mortality may be presented as failure, thereby placing neonatal death and mortality governance within a context of threat. The governance processes that follow a neonatal death provide an opportunity to shape understanding and psychological adjustment to loss for all those affected as well as providing opportunities for whole system learning.

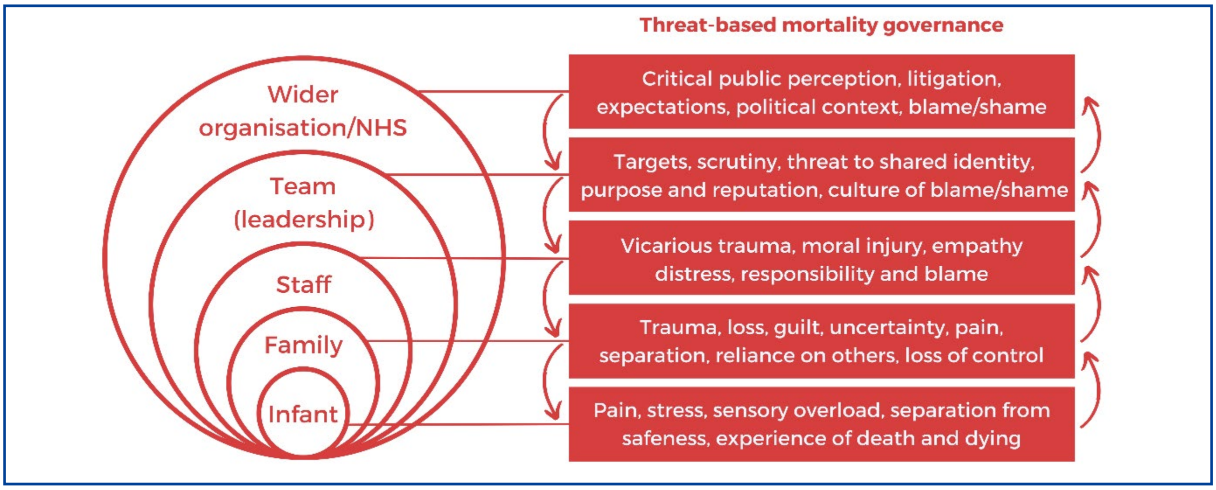
To reduce the psychological impact of neonatal death and mortality governance on parents, families and staff, this framework assumes a trauma informed approach[1], by:

- **Realising** the potential for neonatal loss and related governance processes to be experienced by parents, families and staff as traumatic.
- Supporting staff to **recognise** when people (including themselves) are experiencing trauma in the context of perinatal loss. Outlining pathways for responding to trauma through additional support.
- **Responding** to signs of trauma with appropriate support and signposting.
- **Resisting** re-traumatising parents, families and staff in the way that mortality governance is approached (including how the mortality review process is navigated).

A key role for compassion

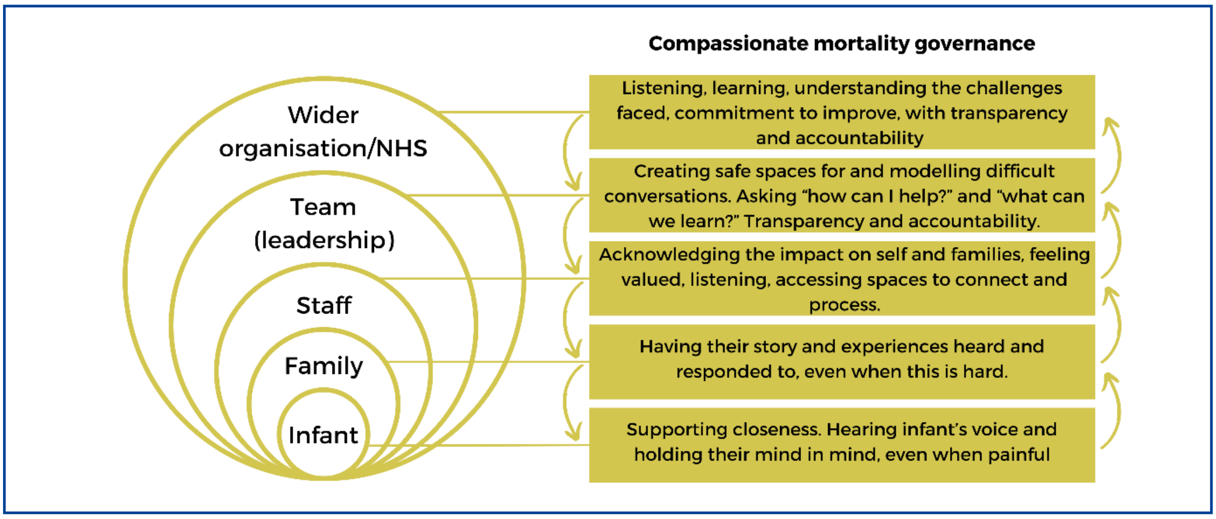
The context of distress and threat inherent in discussions of mortality may hinder learning. For example, fear of criticism and punishment may reduce trust and transparency or lead a team to seek to blame other parts of the baby's care for what happened. It is hard to learn or move forward through grief when faced with a context of threat. Figure A1 illustrates this threat-based approach to assurance processes in mortality review.

Figure A1. A threat-based model of governance, with threat being maintained through interactions between different parts of the system.



When mortality review at an organisational and local level can be approached with compassion, both learning and healing can begin. Compassion entails a sensitivity to the pain and suffering of self and others, with a commitment to relieving that suffering. In the context of mortality review, compassionate wisdom involves having courageous conversations about uncomfortable truths, whilst remaining connected as caring humans to find shared ways forward. Figure A2 illustrates this compassionate approach to assurance processes within mortality review, which is explored in depth by Evans and colleagues[2,3].

Figure A2. A compassionate model of mortality governance, with compassion filtering up and down through the system.



Universal Support for families and staff

Background

The death of a baby is a devastating experience for families, having far-reaching psychological consequences on parents and the wider family[4,5,6,7]. This leads to an increased risk of mental health difficulties in families, including depression, anxiety, post-traumatic stress disorder and suicidal ideation[8,9,10,11]. While the experience of parents (as most often the legal guardians of a baby) is of utmost importance in this framework, the needs of other family members (including siblings, grandparents and extended family members) should also be considered[12].

A detailed discussion of the comprehensive psychological, emotional, social, spiritual and practical support that families need in the period before and after a neonatal bereavement is beyond the scope of this framework. It should be noted that families do not experience the mortality governance process in isolation and so this framework should be read alongside other relevant guidance for high quality bereavement care including the National Bereavement Care Pathway (NCBP)[13].

Staff who work with perinatal loss are at risk of burnout and, relative to their colleagues, elevated levels of post-traumatic stress disorder, depression and psychosomatic symptoms[14]. This impact is greater for staff with lower perceived competence in the work, highlighting the need for adequate skills training (see below).

The skills and support required by staff involved in mortality governance processes go above and beyond bereavement care. Staff involved in perinatal mortality review, coroner's court and child death overview panel have continued contact with families through a time of increased and extended psychological vulnerability. This increases the chance of encountering situations that require coping skills to navigate moral distress, empathy, distress fatigue and secondary traumatic stress. Staff who are well supported (with adequate skills training and wellbeing support) will provide better quality patient care, have greater satisfaction in work and lower sickness absence.

Below is a discussion of the universal support that is needed to support the wellbeing of families and staff through the mortality governance process. To create optimal conditions for system-learning and psychological support within the mortality governance process, the following universal support is needed, to promote the principles of trauma informed care[1]:

- **A felt sense of safety:** Families and professionals feel that they are in a safe environment.
- **Trust & transparency** between families and professionals involved in mortality governance.
- **Collaboration & mutuality** in the relationships between families and professional teams.
- **Peer support** for families and staff.
- **Empowerment, voice and choice** for families within the requirements of statutory processes.
- Sensitivity to **cultural, historical and gender issues**.

Support for families

- **A felt sense of safety**

  Mortality governance processes are intended to reduce uncertainty and provide answers for both families and clinical teams, to better understand the causes and circumstances around a baby's death. Such answers can help parents to feel that their future perinatal care will be safer, or that they have contributed to safer perinatal care more broadly, bringing meaning to their grief and suffering. These processes can, however, expose family members to highly distressing information, and ultimately may not remove uncertainty completely.

  The emotional wellbeing of family members should be born in mind at all time points. This does not mean overly protecting families or avoiding distressing conversations but rather maintaining an open dialogue about what support they need to engage in mortality governance processes in a way that feels safe for them.

- **Trust and transparency**

  Even when governance addresses difficult or uncomfortable truths, it is crucial that communication with families prioritises transparency. Aside from duty of candour, transparency fosters trust, which promotes positive collaborative relationships – benefiting family and team.

  Emotionally attuned, compassionate communication with families is of paramount importance throughout the mortality governance process. 'Being heard' and 'recognised as a parent' are extremely important[15,16]. Insensitivity and poor communication have been highlighted as a factor that causes distress or feelings of helplessness in some cases[15, 17]. Guidelines for effective communication can be found in the Code of Practice for the diagnosis and confirmation of death[12]. However, it should be noted that effective communication is a complex set of relational skills and cannot be adequately conveyed in a written guideline.

  - All staff involved should have access to high quality specialist dialogical communication skills training, including opportunities for experiential, reflective learning with feedback[18].
  - Sands provides a range of specialist training workshops focusing on communication, for staff in clinician and non-clinical roles[19].

  Interpretation services should be used to support good communication if either parent does not speak English fluently. Family members should not be used to interpret[20].

- **Peer support**

  Research and feedback from families repeatedly demonstrates the value of peer support from other families with lived experience following perinatal loss[21]. Families should be able to access such peer support and should be facilitated to do so. This can either be through large organisations such as Sands or local community-based groups. Hospitals teams should develop relationships with local peer support groups and maintain accessible information about how to access this support.

- **Collaboration and empowerment**

  Involvement of families in mortality governance improves dialogue and continuity of care between parents and providers[22] and supports parents to maintain a purposeful role following the death of their baby.

  - All families should have a named lead consultant and a named keyworker (this is a statutory requirement in England) who can act as a consistent point of contact for families to facilitate support, communication and engagement in the process, including involvement in PMRT/CDRM and CDOP meetings[13].
  - The Child Death Review Toolkit contains guidance to support professionals and services to ensure adequate support to families through the process[23].
  - Guidelines for effective communication with families can be found in the Code of Practice for the diagnosis and confirmation of death[12].
  - The level of involvement that families wish to have in the mortality governance process will vary and should be agreed, and continually reviewed, through discussion with the family[24].
  - All information required for the PMRT should be submitted promptly. Teams should have a process to expedite this to prevent unnecessary delays in the CDRM process.

Consensus recommendations from a group of professionals and a parent collaborative group on the engagement of families in the perinatal mortality review process gave the following recommendations which you may wish to consider[25]:

1. There should be a face-to-face explanation of the perinatal mortality review process, supported by a written information leaflet, prior to hospital discharge.
2. The form to obtain parental feedback should be completed in a face-to-face consultation at a private location of the parents' choice (if declined, option to receive feedback by telephone, e-mail or post should be offered).
3. The parents should be offered the opportunity to nominate a suitable advocate or bereavement-care midwife or nurse, who will complete the feedback form with the parents and attend the perinatal mortality review meeting.
4. All healthcare professionals involved in the case should be notified of the perinatal mortality review meeting in good time and attend where possible.
5. Staff involved in the case who cannot attend the perinatal mortality review meeting should, at the very least, submit their comments.
6. Responses to the parental feedback should be formally documented in the perinatal mortality review meeting.
7. If necessary, action plans should be made from the parental responses and monitored.
8. A plain-English summary should be produced for the parents following the perinatal mortality review meeting.
9. The feedback from the perinatal mortality review meeting should be discussed at the consultant follow-up meeting, supported by the plain-English summary.
10. The consultant follow-up meeting should take place as soon as possible after the perinatal mortality review meeting (approximately 2–4 weeks).
11. Parents should have the option to nominate a second member of staff (who could be the designated parents' advocate) to attend the follow-up meeting with the consultant.
12. If the parents decline to attend the consultant follow-up meeting, then the written plain-English summary should be offered to be sent to the parents instead.
13. There should be four different parental feedback forms (for stillbirth, neonatal death, coroner's case and termination for fetal abnormality).
14. The meeting should take place within approximately 12 weeks from the baby's death.

- **Cultural and spiritual sensitivity**

  Care should be sensitive to the intersectional cultural, spiritual and individual identities and needs of families. Different families observe diverse important practices around the death of a baby, and cope with bereavement in different ways[26]. Specific guidance and information can be found in existing resource[27,28] . Online training is provided by The Lullaby Trust to aid in understanding the cultural context of grief[29].

  It is paramount to ask all families what their preferences and needs are for all stages of the mortality governance process, and not to make assumptions that parents have specific wishes based on their cultural or religious backgrounds. This should be particularly born in mind when considering the timescale of the process, and the use of devices such as cool cots, as some communities have particular requirements regarding the timing of a baby's funeral. These choices should be documented on the Bereavement Care Checklist and reviewed where they are relevant to processes such as rapid release[13].

  Families should be empowered to be parents and make memories throughout their baby's life as part of family integrated care[30]. Families may find that a process of memory making at or near the end of life aids the process of grief and loss[31]. Clinical staff should discuss this with families at an early stage to understand what meaningful memory making might involve for each family[32,33]. The offer of memory making should be recorded on the Bereavement Care Checklist. This enables an evaluation of family experience and trauma informed practice at the CDRM[13].

  Chaplaincy within the hospital setting can be a helpful resource to facilitate families' preferences from an early stage, as well as community and religious or spiritual leaders from the family's own network.

  To ensure accessibility of the whole mortality review process, all written materials should be available in a range of languages appropriate for the local population served.

Support for staff

- **A felt sense of safety**

  When staff feel safe to ask for help, share struggles and name mistakes, the safety and quality of care improves as does the wellbeing of the staff team. Such psychological safety is crucial to consider when approaching learning events such as mortality review meetings, system or network-wide shared learning events.

  Whilst accountability (taking ownership of actions and their consequences) is an important positive step for learning and development, blame (assigning fault and responsibility for a death) is unhelpful and reliably undermines psychological safety. Blaming leads to shame which inhibits learning. Blame is a common response when people acting from the psychological experience of threat seek to understand the causes of an incident. Psychological safety is a culture in which people feel able to name their mistakes or difficulties without fear of blame or judgement. Psychological safety does not ignore mistakes or difficulties. Rather it holds people accountable for their actions, but without resorting to blame and shame.

  Psychological safety is fostered through cultures of openness, humility and compassion, where the intention is to ask "What help do we need?" rather than "Who is to blame?" There are well evidenced reasons why this is difficult and requires significant scaffolding across all layers of the system[2]. Practical steps towards compassionate, psychologically safe maternity and neonatal cultures are outlined by Evans and colleagues[3]. Psychological safety in a team is facilitated through other collective, connecting approaches such as reflective practice sessions and group supervision.

It is important that staff feel safe in their workplace and should expect to be treated reasonably by other stakeholders, such as parents, colleagues, their employing organisation and external representatives e.g. HMC/PF/MNSI/external reviewers. Trusts should have processes in place to respond constructively if this does not happen.

- **Trust and transparency**

  Transparency of information sharing and communication both within and between teams is crucial, to foster trusting relationships. Trust and transparency contribute to a culture of accountability and learning, and provides the connected relationships that facilitate feelings of belongingness and wellbeing.

  Debrief is one activity where transparent sharing of information can occur, in addition to other key meetings and forums such as mortality review meetings. Detailed consideration of debriefing practice is discussed below.

- **Peer support**

  Peer support should be facilitated both within and between teams. Peer support is about fostering a community with shared identity and relational safety – rather than simply providing a forum for shared learning. Debrief is one way to approach this. Other approaches include trained peer supporters within a staff group who can facilitate access to additional support. Neonatal Networks and local systems are well placed to facilitate peer support, especially between staff from different types of unit to promote transparency and broaden the community of support beyond the immediate team.

- **Collaboration and empowerment**

  Staff, regardless of their position or seniority, who have been involved in the care of a baby who dies should be empowered to have an active voice in the mortality governance processes that follow. This can follow the principles outlined in the Patient Safety Incident Response Framework[34] (PSIRF). Although not all neonatal deaths will be responded to formally using PSIRF, the underlying principle of compassionately involving all those impacted by the neonatal death (family members and staff) provides a helpful framework to guide support from staff.

  Other pathways of reporting can empower staff to contribute their voice to mortality governance, including Maternity and Neonatal Safety Champions, and Freedom to Speak Up Guardians. All trusts should ensure that such roles are in place, adequately resourced and easily accessible to all staff in the team. BAPM has produced guidance on 'How to Raise a Concern' for neonatal professionals[35] if such actions are required.

- **Cultural and spiritual sensitivity**

  Staff bring with them personal beliefs about death and dying – shaped by their culture, spirituality, gender and more – which impact on their experience of working with families who suffer a neonatal death. Care should be centred around the beliefs and experiences of families. This means that the intersection of the personal beliefs of family and staff can sometimes lead to significant moral distress for staff – where they are being asked to provide care that threatens or even violates their moral code. Staff should have the opportunity to reflect on their own intersectional identities and how this shapes their beliefs about the work that they are doing.

Targeted Support for families and staff

There are particular groups who may need targeted or particularly tailored support through mortality governance processes, to ensure they are able to access the universal information and support available. When targeted or tailored support is indicated for families, this should be recorded in Bereavement Care plans and the appropriateness/timeliness of this support should be discussed at the CDRM. Where appropriate, psychological actions should be included in PMRT Action Plans and monitoring undertaken. The information below is not exhaustive and providers should discuss any particular support needs with families individually.

Support for families

- **Parents with further needs**

  Parents of babies in neonatal care are individuals with a diverse range of needs, some of which might require further adaptations. These needs might include neurodivergence, physical or learning disability (with associated accessibility needs), low levels of spoken English, low levels of literacy. Following from these needs, parents may have specific ways of thinking about death and associated rituals. They might need additional support, in the way of adapted communication, to understand the feelings and behaviour of other people, or to understand what has happened, and what might happen next in the process.

  As with all families, the best way to support a person with further needs is to get to know them, their strengths and their particular needs especially around adaptations to assist them in processing and communicating information. .

  Some parents or family members, as a result of these additional needs, might have a reduced ability to understand new or complex information; struggle to learn new skills; and have difficulty coping independently. This group are at risk of exclusion from services due to a lack of adequate tailored support. The production of easy-read information resources in multiple languages; interpretation services; the use of advocacy services or other specialist professionals (such as learning disability nurses, social workers, psychiatrists, psychologists or speech and language therapists); and additional time and flexible arrangements to allow for processing of complicated information can help.

- **Children and young people**

  Although child siblings will not likely be directly involved in mortality governance processes, they may well have questions and needs arising from the information that is shared with their family. In some instances, young parents themselves may still be children. A list of resources available to support children, young people and those with special educational needs, in their understanding of bereavement can be found on the Child Bereavement UK website[36].

- **Families going through coronial proceedings**

  The particular stresses of a coroner's investigation cannot be underestimated. In fact, the counter-therapeutic impact for families of coronial investigations has been highlighted[37]. Families report valuing the presence of an advocate, either from within their existing network or from a professional organisation such as the Coroners Court Support Service[38].

Support for staff

There are particular groups who are more likely to experience a detrimental psychological impact of this work, by the nature of and proximity to their work. This includes staff who are directly involved in specific mortality governance processes, such as Child Death Review Keyworkers; bereavement midwives and nurses; staff involved in PMRT or CDOP, and any staff who are required to contribute to a coronial investigation. For these staff, restorative spaces such as clinical supervision, psychological case consultation and reflective practice groups can help mitigate the risks linked to the job. Professional Nurse Advocates are able to provide restorative clinical supervision, and specialist psychological professionals provide this range of interventions when integrated into the team.

Other processes such as Trauma Risk Management (TRiM) can be helpful to implement across provider trusts, and can be helpful to trigger following the death of a baby, to facilitate the recognition of those staff members who might benefit from additional support.

Specialist Support for families and staff

Support for families

For some families, particularly when there are already mental health difficulties or there is previous trauma present, the death of a baby can result in a deterioration in their mental health. To provide safe and inclusive mortality governance processes, providers should ensure:

- **Skills in screening for mental health difficulties**
  Clinical staff working with families who have experienced bereavement, particularly during mortality governance processes, should be provided with training to recognise and identify signs of common mental health difficulties (see Support for staff section).
- **Signposting to services for the provision of mental health support**
  There is emerging evidence for psychological interventions to support the mental health of parents following perinatal loss[39] including cognitive behaviour therapy, and eye movement desensitisation and reprocessing[40]. Providers should have clear pathways of referral to local services such as local psychiatric support, NHS Talking Therapies, Maternal Mental Health Services, or their GP, to facilitate access to this support.
- **Psychological professionals integrated into the multidisciplinary team**
  The ability of staff teams to recognise and respond effectively to the psychological needs of families is significantly enhanced by the integration of psychological professionals into the multidisciplinary neonatal team[41]. Specialist neonatal psychological professionals can facilitate training, case consultation, reflective supervision to the team caring for families through mortality governance processes and also provide bereavement-focused psychological interventions where this is indicated.

Support for staff

When staff experience a deterioration in their mental health as a result of the emotional labour of their work with mortality, they should be able to access support from a range of sources. Above all, trusts should ensure that this support is easy to access, clear and responsive. The support should be multi-faceted to ensure that all staff needs can be addressed, including:

- Trust-wide psychological staff support services
- Employee assistance programs
- Occupational health services
- Practitioner Health
- Local external providers (e.g. NHS Talking Therapies)

Above all, it is of utmost importance that psychological professionals are integrated into the neonatal MDT. These specialists facilitate the recognition and signposting of mental health difficulties within the staff team related to the impact of working with death and dying, and can also offer focused interventions that are highly accessible. The uptake and effectiveness of support for staff should be monitored using staff well-being markers, including retention and absence data, to ensure it meets needs.

Debriefing

Clinical teams should develop clear and consistent pathways of debriefing following the death of a baby. There are many different models and approaches to debriefing, with detailed protocols available at the Paediatric Innovation, Education and Research Network (PIER) website[42]. Key to effective debriefing, is to approach with flexibility, addressing the clinical or emotional concerns of those present rather than being rigidly constrained by a protocol.

Common approaches to debriefing contrast “hot debrief” – carried out immediately after an incident, or within the same shift – and “cold debrief” – carried out in the days or weeks following an incident.

Hot debrief

The aim of a “hot debrief” is to ensure that any immediate safety concerns (both clinical and related to patient and staff wellbeing) are addressed in a timely manner. There may be specific questions that team members need to voice, answering which may prevent unhelpful patterns of rumination and catastrophic thinking for some. There are different published protocols for hot debrief, such as that available at the PIER website[41] or STOP5[43].

Cold debrief

“Cold debrief” is an umbrella term for multiple different types of conversation, which have different aims and intentions. The process and content of a cold debrief will differ according to the aim and intent. Therefore, it is crucial to be clear about the intended aim before convening a cold debrief. The three primary types of debrief, identified by Kolbe and colleagues[44] are:

- **Debriefing to learn**.

Aim: This is a clinical governance-focused activity, with the intention of learning from what has happened. The aim is to identify areas of strong clinical practice and development needs within the team and its standard care processes. Learnings from a debrief should be documented and captured into PMRT/CDRM Action plans.

Content: Details of the chronology and clinical scenario are examined from different angles. More detail about “debriefing to learn” can be found at PIER[41].

- **Debriefing to manage**.

Aim: This is a wellbeing-focused activity, with the intention of addressing the psychological needs of staff, to promote a culture of psychological safety, feelings of calm, self-efficacy, hope and connection[45]. The aim is to promote connection between members of the team and shared narratives.

Content: Staff share stories of their emotional responses to the incident and their resonance with colleagues is explored. Detailed guidelines for the facilitation of “debriefing to manage” (also known as “Post-Event Team Reflection) by specialist psychological professionals or other mental health professionals has been produced by the Association of Clinical Psychologists[46].

- **Debriefing to treat**.

Aim: This is an interventional activity, with the intention of undertaking group treatment for trauma-related psychological difficulties.

Content: **This is counter-indicated by the literature, can cause psychological harm and should not occur.**

Supporting skill development for staff
Staff need training that covers the range of competencies outlined below. Particularly for interpersonal and relational skills, initial training delivery should be followed by continued opportunities to embed learning through experiential and reflective practice (including simulation, video feedback guidance, reflective practice or supervision groups and psychological debrief[18]). Training for all staff should cover:

- High quality bereavement care, in line with National Bereavement Care Pathway (NBCP) guidance :
    - https://training.sands.org.uk/

  Other national bereavement care training:
    - www.childbereavementuk.org/training
- Best practice in perinatal palliative care; free NHS resources based on the BAPM palliative care framework
    - Introduction to Neonatal Palliative Care
    - Future Learn: Managing Uncertainty in Perinatal Medicine and Palliative Care OR My Learning Hub: Managing Uncertainty in Perinatal Medicine and Palliative Care
- Support for families following loss of a baby in multiple pregnancy. Resources available at:
    - www.neonatalbutterflyproject.org
- Recognition and signposting of mental health deterioration, for example:
    - https://mhfaengland.org
- Cultural competence around death and dying. National providers include:
    - www.lullabytrust.org.uk/professionals/training/bereavement-training
- Compassionate communication:
    - https://training.sands.org.uk

Training for staff involved in specific processes should cover:

- Post-mortem consent taking. E-learning for this topic can be accessed:
    - www.e-lfh.org.uk/programmes/perinatal-post-mortem-consent
- The role of the child death review keyworker
    - See www.ncmd.info for details
- Managing lactation in the event of neonatal loss
    - e-learning Lactation after loss
    - www.bapm.org/resources/lactation-and-loss-management-of-lactation-following-the-death-of-a-baby
    - Breastfeeding Network has more information on training specific to lactation www.nationalbreastfeedinghelpline.org.uk

- Debrief. There are multiple models of debrief, for which training is available, including Post-Event Team Reflection; Critical Incident Stress Debriefing; Trauma Risk Management.

A range of learning resources are outlined in the Care After Death guidance (5th edition) produced by Hospice UK[47].

References

---

[1] Substance Abuse and Mental Health Services Administration. SAMHSA's Concept of Trauma and Guidance for a Trauma-Informed Approach. 2014

[2] Evans D, Butterworth R, Atkins E, Chilvers R, Marsh A, Barr K, et al. The anatomy of compassion: courage, connection and safeness in perinatal practice. Infant. 2023;19(3):88–92.

[3] Evans D, Butterworth R, Atkins E, Barr K, Chilvers R, Cole S, et al. The anatomy of compassion part 2: nurturing compassionate cultures of maternity and neonatal care. Infant. 2023;19(6):213–8.

[4] Bothou A, Bothou M, Tsikouras P, Iatrakis G, Anthoulaki X, Chalkidou A, et al. Consequences of perinatal mortality in parents' psychology and the role of health professionals in its management. Rev Clin Pharmacol Pharmacokinet Int Ed [Internet]. 2023 Oct;35(2):67–74. Available from: https://doi.org/10.5281/zenodo.10048497

[5] Aydin R, Kabukcuoğlu K. Fathers' Experiences of Perinatal Loss: A Sample Meta-Synthesis Study. J Fam Issues [Internet]. 2021;42(9):2083–110. Available from: https://doi.org/10.1177/0192513X20966002

[6] Lockton J, Oxlad M, Due C. Grandfathers' Experiences of Grief and Support Following Pregnancy Loss or Neonatal Death of a Grandchild. Qual Health Res [Internet]. 2021;31(14):2715–29. Available from: https://doi.org/10.1177/10497323211041331

[7] Kirui KM, Lister ON. Lived Experiences of Mothers Following a Perinatal Loss. Midwifery. 2021 Aug;99:103007.

[8] Christiansen DM. Posttraumatic stress disorder in parents following infant death: A systematic review. Clin Psychol Rev. 2017 Feb;51:60–74

[9] Gausia K, Moran AC, Ali M, Ryder D, Fisher C, Koblinsky M. Psychological and social consequences among mothers suffering from perinatal loss: perspective from a low income country. BMC Public Health [Internet]. 2011;11(1):451. Available from: https://doi.org/10.1186/1471-2458-11-451

[10] Herbert D, Young K, Pietrusińska M, MacBeth A. The mental health impact of perinatal loss: A systematic review and meta-analysis. J Affect Disord. 2022 Jan;297:118–29.

[11] Bright A-M, Doody O, Tuohy T. Women with perinatal suicidal ideation-A scoping review of the biopsychosocial risk factors to inform health service provision and research. PLoS One. 2022;17(9):e0274862.

[12] Academy of Medical Royal Colleges. A Code of Practice for the diagnosis and confirmation of death 2025 Update. 2025.

[13] Sands Charity. National Bereavement Care Pathway for stillbirth and baby loss. [online]. NBCP for stillbirth and baby loss

---

[14] Gandino G, Bernaudo A, Di Fini G, Vanni I, Veglia F. Healthcare professionals' experiences of perinatal loss: A systematic review. J Health Psychol. 2019 Jan;24(1):65–78.

[15] Lundqvist A, Nilstun T, Dykes A-K. Both empowered and powerless: mothers' experiences of professional care when their newborn dies. Birth. 2002 Sep;29(3):192–9.

[16] Redshaw M, Henderson J, Bevan C. "This is time we'll never get back": a qualitative study of mothers' experiences of care associated with neonatal death. BMJ Open. 2021 Sep;11(9):e050832.

[17] Gold KJ, Dalton VK, Schwenk TL. Hospital care for parents after perinatal death. Obstet Gynecol. 2007 May;109(5):1156–66.

[18] Rosenbaum ME, Silverman JD. Training for Effective Communication in Healthcare Settings. In: Martin L., DiMatteo R, editors. The Oxford Handbook of Health Communication, Behavior Change, and Treatment Adherence. Oxford: Oxford University Press; 2014.

[19] Sands. Bereavement Care Training. https://training.sands.org.uk/bereavement-care/.

[20] Sands and Bliss. Audit of bereavement care provision in UK neonatal units 2018. [online]. Audit of bereavement care in neonatal units

[21] Zhuang S, Chen M, Ma X, Jiang J, Xiao G, Zhao Y, et al. The needs of women experiencing perinatal loss: A qualitative systematic review and meta-synthesis. Women Birth. 2023 Sep;36(5):409–20.

[22] Burden C, Bakhbakhi D, Heazell AE, Lynch M, Timlin L, Bevan C, et al. Parents' Active Role and ENgagement in The review of their Stillbirth/perinatal death 2 (PARENTS 2) study: a mixed-methods study of implementation. BMJ Open. 2021 Mar;11(3):e044563.

[23] National Child Mortality Database. https://www.ncmd.info/guidance/parents-cdr-toolkit/.

[24] Bakhbakhi D, Siassakos D, Burden C, Jones F, Yoward F, Redshaw M, et al. Learning from deaths: Parents' Active Role and ENgagement in The review of their Stillbirth/perinatal death (the PARENTS 1 study). BMC Pregnancy Childbirth [Internet]. 2017;17(1):333. Available from: https://doi.org/10.1186/s12884-017-1509-z

[25] Bakhbakhi D, Siassakos D, Lynch M, Timlin L, Storey C, Heazell A, et al. PARENTS 2 study: consensus report for parental engagement in the perinatal mortality review process. Ultrasound Obstet Gynecol Off J Int Soc Ultrasound Obstet Gynecol. 2019 Aug;54(2):215–24

[26] Fernández-Basanta S, Coronado C, Movilla-Fernández M-J. Multicultural coping experiences of parents following perinatal loss: A meta-ethnographic synthesis. J Adv Nurs. 2020 Jan;76(1):9–21.

[27] North West Neonatal Operational Delivery Network. https://www.neonatalnetwork.co.uk/nwnodn/wp-content/uploads/2017/06/NWNODN-Religious-Practices-.pdf

[28] Child Bereavement UK. https://www.childbereavementuk.org/pages/faqs/category/faiths-beliefs-cultures-and-communities#.

[29] Lullaby Trust. https://www.lullabytrust.org.uk/professionals/training/bereavement-training/.

---

[30] British Association of Perinatal Medicine. Family Integrated Care. A Framework for Practice. 2021 https://www.bapm.org/resources/ficare-framework-for-practice

[31] Clarke T, Connolly M. Parent's Lived Experience of Memory Making With Their Child at or Near End of Life. Am J Hosp Palliat Care. 2022 Jul;39(7):798–805.

[32] Bliss. Bereavement Support for you and your family. Bliss Bereavement Support

[33] Together for Short Lives. Family Hub support. https://www.togetherforshortlives.org.uk/get-support/

[34] England N. Patient Safety Incident Response Framework [Internet]. Available from: https://www.england.nhs.uk/patient-safety/patient-safety-insight/incident-response-framework/

[35] British Association of Perinatal Medicine. How to raise a concern [Internet]. Available from: https://www.bapm.org/resources/how-to-raise-a-concern

[36] Child Bereavement UK. https://www.childbereavementuk.org/FAQs/supporting-bereaved-children-and-young-people-with-sen.

[37] Freckelton I. Minimising The Counter-Therapeutic Effects Of Coronial Investigations: In Search Of Balance. QUT Law Rev. 2016;16(3):4–29

[38] Coroners Court Support Service. https://coronerscourtssupportservice.org.uk/.

[39] Shaohua L, Shorey S. Psychosocial interventions on psychological outcomes of parents with perinatal loss: A systematic review and meta-analysis. Int J Nurs Stud. 2021 May;117:103871.

[40] National Institute for Health and Care Excellence. Antenatal and postnatal mental health: clinical management and service guidance [Internet]. 2020. Available from: https://www.nice.org.uk/guidance/cg192

[41] Atkins E, Barr K, Butterworth R, Chilvers R, Cole S, Cordwell J, et al. Psychology Staffing on the Neonatal Unit: Recommendations for Psychological Provision [Internet]. 2022. Available from: https://hubble-live-assets.s3.amazonaws.com/bapm/redactor2_assets/files/1241/Psychology_Staffing_on_the_Neonatal_Unit.pd

[42] Paediatric Innovation Education and Research Network. https://www.piernetwork.org/debrief.html.

[43] Walker CA, McGregor L, Taylor C, Robinson S. STOP5: a hot debrief model for resuscitation cases in the emergency department. Clin Exp Emerg Med. 2020 Dec;7(4):259–66

[44] Kolbe M, Schmutz S, Seelandt JC, Eppich WJ, Schmutz JB. Team debriefings in healthcare: aligning intention and impact. BMJ. 2021 Sep;374:n2042.

[45] Archibald S-J, O'Curry S. Reflections on developing a protocol for pre and debriefs on a neonatal intensive care unit (NICU). J Neonatal Nurs [Internet]. 2020;26(4):192–6. Available from: https://www.sciencedirect.com/science/article/pii/S1355184120300156

---

[46] Association of Clinical Psychologists. Group Psychological ‘Debriefs’: Practice guidance for post-event team reflection (PETR) following distressing events at work [Internet]. 2024. Available from: https://acpuk.org.uk/wp-content/uploads/2024/08/Group-Psychological-Debriefs.pdf

[47] Hospice UK. Care After Death Guidelines [Internet]. Available from: https://www.hospiceuk.org/innovation-hub/clinical-care-support/care-after-death