

Example of a perinatal palliative care plan

Information for the care team

- Names of parents, baby, other significant family/whānau members such as siblings and grandparents
- Summary of pregnancy journey and value-driven goals of care
- Names and contact information for key care team members and family/whānau/social supports
- Use of a universal identifier (symbol) to indicate that a baby has died or has a life-limiting condition

Care of the mother (Continuum: pregnancy, birth, postpartum care plan)

- Antenatal planning including:
 - individualised childbirth classes
 - antenatal care schedule: what, where, when, who
 - timing and mode of birth
 - parent-centred hopes for the experience of birth (people to be present, creation of desired environment, plans for pain management, cutting of the umbilical cord, photographs, cultural needs, etc.)
 - parental wishes for fetal heart rate assessment during labour, including agreed upon approach to fetal distress
 - resuscitation extent (or not)
- Postpartum planning including:
 - immediate postpartum care: where, what, time
 - newborn-parental bonding: parenting; holding, seeing, and touching newborn; skin-to-skin (or swaddling) contact
 - maternal self-care after delivery
 - family/whānau care

Care of the newborn (Palliative care plan)

- Care for the baby, specifying a focus on
 - comfort care (agreed goals, warmth, hydration, feeding, pain/distress) versus
 - medical stabilisation/actions (e.g., desire for oxygen to be used, effort, pain/distress as ordered)
 - describe any limitations to the degree of intervention and/or identify indications for redirecting care goals
- Description of parent and family/whānau plans for the first moments of life (additional visitors, introduction to significant family/whānau members, special prayer/blessing/ritual, use of special mementoes, etc.)
 - Feeding plan (and any limitations due to condition)
 - Role of lactation consultant in breastfeeding/breastmilk goals, if requested
- Plans for additional diagnostic testing (cord blood for genetics, echocardiogram, x-ray, etc.)
- Symptom management if comfort-focused newborn care with anticipated end-of-life signs discussed
- If medical evaluation is planned, location of ongoing newborn care and recommended communication with team members discussed

Care of the family/whānau (Bereavement care plan)

- Anticipated opportunities for memory-making (photography; handprints, footprints, or moulds; heartbeat recording, etc.)
- Social and emotional support and referral to local services and parental support organisations
- Cultural, religious, and spiritual rituals needs or requests
- Inclusion and support of other significant family/whānau members as appropriate
- Consideration of continuing care in community/home

Details of care coordination

- Plans for continuing care by multidisciplinary care regarding any ongoing needs or planned evaluations
- Plans for ongoing care if baby remains alive (details for admitting to home-based care or inpatient hospice, anticipated home care needs planned and documented with appropriate referrals to other providers, etc)
- Plans for care of baby's body after death, including documentation of discussions regarding postmortem investigations, organ donation (if available and desired), cremation or burial, identified funeral home)

This plan is adapted from Table 2 of Humphrey & Schlegal (2022).