Model of care and principles of palliative and end-of-life care for babies

Any baby (in utero or post-natal) requiring palliative and end-of-life care

Model of care overview

Diagnosis
- Discuss—prognosis (quiet, private environment)
- Introduce—palliative care principles (early)
  - o Can be concurrent with curative or disease-modifying treatment
- Support—early referral and connection
- Allocate—a key point/s of contact
  - o To coordinate care and maintain communication

Condition-specific care planning
- Use multidisciplinary teams
- Update plans regularly based on:
  - o Baby's condition/changes
  - o Parent and family values, goals and preferences
- Plan:
  - o Delivery mode
  - o Location of care
  - o Resuscitation plans
  - o Pain and symptom management/ comfort care
  - o Considerations for provision of nutrition
  - o Medical Interventions
  - o Spiritual and cultural considerations—blessing, naming ceremony
  - o Memory making
  - o Sibling support—if applicable

Palliative care
- Focus on:
  - o Symptom management
  - o Comfort and dignity
  - o Quality of life
- Memory-making
- Reduce or withdraw of life-prolonging treatments
- Coordinate curative and palliative care approaches

End-of-life and bereavement care
- Shift focus to:
  - o Comfort
  - o Dignity
  - o Emotional support
- Integrate bereavement planning and memory-making activities into care
- Provide ongoing support to families

Anticipatory planning
- Advance Care Planning
  - o Commence early
  - o Review regularly
  - o Multidisciplinary input
- Parallel planning
  - o Plan for ongoing care alongside end-of-life care
  - o Plan for unexpected outcomes
- Investigation planning
  - o Antenatal—inform prognosis, guide planning, enable early multidisciplinary care
  - o Postnatal—assess condition, confirm diagnosis, guide symptom management
  - o After death—inform future pregnancies, contribute to clinical knowledge

Principles
- Care begins at diagnosis (antenatally or postnatally)
- Care is:
  - o Active and planned
  - o Flexible and responsive
  - o Holistic, integrated and supportive
  - o Family-centred
  - o Delivered by a coordinated, multidisciplinary team
  - o Delivered across hospital, hospice, home, community and relevant Aboriginal and Torres Strait Islander community health services
- Focus on—comfort, dignity, baby's best interests
- Partner with parents and families
- Develop individualised care plans
- Respect family values
- Consistent, coordinated, and compassionate support for families
- Support:
  - o Continuity, memory-making, bereavement
  - o HCP through education and debriefing

HCP: Healthcare providers/professionals

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