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Wales Maternity and Neonatal Network

Extreme Preterm Pathway (document 4)
Comfort Care Pathway

Background

Palliative care must be in the best interests of the baby, agreed where there is extremely high risk of a poor outcome for the baby and a decision made not to offer a survival-focussed management. A detailed documented consultation with parents involving senior clinical staff from obstetric, midwifery and as appropriate neonatal team is paramount.

Palliative care involves transitioning a baby from life-saving interventions to providing ''comfort care'' which consists of providing warmth, pain medication and most importantly intimate contact between parents and their baby. The focus is on the family's quality of life during their time spent together.

This care should be delivered in the most appropriate location for the family (which is not necessarily a neonatal unit) and should not necessitate in utero transfer. The obstetric/maternity team in a dedicated bereavement room should deliver care (where available). There should be an emphasis on family-centred care with an opportunity for parents to create positive memories of their baby.

Intrapartum fetal monitoring is not recommended. Parents should be informed that their baby may show signs of life after birth; visible heartbeat, gasping, movement of limbs. Parents should also be advised of what their baby will look like (extreme preterm information leaflet should be given to parents).

Baby and family should be treated with respect, dignity and privacy. Parents should be offered the opportunity to hold and spend as much time as they wish with their baby in a quiet and private location.

On average babies born before 24 weeks of gestation who receive comfort care in the delivery room live for approximately 60 minutes (range from a few minutes to several hours)

Pharmacological symptom management may be considered.

After the baby has died a parent-led bereavement care plan should be put in place for the family, including communicating with parents and creating memories.

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Palliative care

Palliative care centres around the provision of dignity and respect for the baby and family. Support for the parents and extended family initially focuses on interventions for anticipatory grief and ensuring appropriate family bereavement. Parents must feel in control of the events before and after the death.

Aspect	Considerations
Planning care	• Develop an agreed care plan with the family, including as appropriate to the circumstances: o Post-delivery Management o After death care • Discuss the possibility that the baby may live for many hours • Review and amend the plan at frequent intervals to ensure the goals of care are being met • Involve palliative care specialists as appropriate/required • Document decisions in detail to ensure a clear and unambiguous understanding by the health care team and the family
Newborn care	• Handle baby gently and carefully • Provide wraps for cuddling and holding baby • Offer skin to skin contact • Offer opportunities and support the family's wishes to engage in care provision (e.g. nappy changes, bathing, cuddling/holding)
Nutrition/ hydration	• Insertion of a gastric tube for feeding is not usually recommended at extremely low gestational ages but oral feeds may be considered in some circumstances (e.g. via syringe drop) • Maintain oral hygiene and comfort (e.g. moisten lips)
Review all interventions	• Consider individual circumstances and parental wishes in timing these decisions • Prepare the family for the likely/possible clinical sequelae that may follow non-initiation of support (e.g. gasping agitation, tachypnoea, intercostal recession) interventions that increase comfort • Provide sensitive emotional support and reassurance to parents throughout the process and afterwards

Reference: Queensland Clinical Guideline: Perinatal care at the threshold of viability

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Symptom management

- Always assess the need for pain management
- Consider use of established pain scales
- Avoid invasive procedures
- Administer analgesics/sedation as indicated: Welsh Palliative Care Guideline: Anticipatory Prescription access
- Select the route (buccal or enteral) of administration that is best tolerated by the baby. It is unusual to administer anything in this scenario and there is no iv access.Incorporate non-pharmacological interventions (e.g. minimal noise/light, stimuli, flexed position of arms and legs, massage)

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Bereavement support

The loss of a baby is a very emotional and difficult experience for everyone who is involved. It can be difficult to know how to respond to grieving families and you might be worried about saying the wrong thing, but saying nothing at all can be worse.

Aspect	Considerations
Psychosocial	• Maintain a family centred approach to care • Advise the family that the duration of the dying process is variable • Provide an environment conducive to family interaction (e.g. room with recliners/beds, lighting that can be dimmed, outlets where music can be played, access to a kitchenette and bathroom) • Facilitate unrestricted visiting • Facilitate spiritual/religious/cultural rituals, services and support important for the family (e.g. baptism, naming ceremony) • The Spiritual Care Team (Chaplaincy Department) can meet the family, or to support the staff in pursuing and offering appropriate rituals to commemorate the baby
Memory creation	• Facilitate memory creation/gathering before and after death consistent with the family's wishes and following consent (e.g. identification tags, hand and footprints, digital photos, cot cards, hair collection) Offer options to include extended family (e.g. photographs of family group relatives/siblings to hold baby) • Offer option to take baby home if feasible
Follow-up	• Offer assistance with certification and registration of death • Provide information on burial and cremation (written or verbal) • Offer a future appointment to discuss the death with the health care team, particularly the lead health care professional • Provide contact information for psychological support (e.g. professional counselling or support groups/organisations) • Consider care needs for subsequent pregnancies • Staff support is essential i.e. debriefing, supervision

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APPENDIX 1: CHECKLIST FOLLOWING A NEONATAL DEATH
(PS: Use your local Health Board's document if available)

	TICK	COMMENTS	DATE SIGN
Parents informed of death by:			
Baby seen by parents			
Obtain consent from parents for photos and mementoes			
Photographs taken for parents, offer a family photograph.			
Contact hospital photographer			
Give parents Bereavement boxes Cot card Identity band Lock of hair Foot/hand print			
Chaplain / parents own religious advisor notified			
Has any religious/non-religious support been offered e.g. naming ceremony, blessing.			
Is death a Coroners case? YES NO (Unexpected, Unexplained) Dr Informed Coroner YES NO Safeguarding Team informed YES NO PRUDIC required YES NO			
Request for post mortem examination completed by Dr (to go to mortuary with completed notes whether hospital or coroners post mortem)			
NO CONSENT FOR PM IS REQUIRED IF CORONERS' PM Post mortem. Consent given / refused. (Not required for coroners) Contact Mortuary technician for advice if necessary			
Medical certificate of cause of death completed, **(NOT FOR CORONERS CASE)** **NB Dr must print their name above the signature and write down their GMC number**			
Discuss funeral arrangements with parents e.g. burial or cremation			
Is a cremation form needed			

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Parents informed on where & when to register birth & death Inform parents that they need to phone to make an appointment at registry office Directions given			
	TICK	COMMENTS	DATE SIGN
Medical certificate on cause of death explained & and given to parents			
Phone Registrar's office (so that they are aware of parents coming to register death)			
If Parents wish to take Baby home (**not if coroner's case)** Discuss with mortuary technician Site Manager & Consultant informed Police aware Mortuary Ledger completed Medical certificate completed Cremation certificate completed if required Advisory letter given Death must be registered prior to leaving hospital			
Give parents the Bereavement support officer's card (if available)			
Inform family about HB Remembrance services (if available)			
Inform parents that they will have an appointment to speak to a Paediatrician at a later date			
Inform mortuary prior to taking baby to mortuary			
Label baby and transport to mortuary			
Consultant Paediatrician informed			
Community midwife informed			
Neonatal outreach team informed			
GP informed Death Advice letter in pack to be filled in by Drs.			
Inform Hospital Site manager			
Health Visitor informed			
Child health department informed to stop vaccination appointments being sent			
CARIS form			
MBRRACE Co-ordinator informed, using notification form			

Reference:

1. Queensland Clinical Guideline, Perinatal Care at threshold of Viability, September 2014, document number MN14.32-V1-R19.
2. Katrina Kelly, Together for Short Lives: Standards framework for children's palliative care v3, July 2015 and A Perinatal Pathway for Babies with Palliative Care Needs Second edition 2017.
3. Larcher V, et al. Arch Dis Child 2015;100 (Suppl 2):s1–s23. doi:10.1136/archdischild-2014-306666

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