

PATHWAY FOR THE CARE OF NEONATES AND THEIR FAMILIES AT END OF LIFE IN THE NEONATAL UNIT

**National Implementation Group,
HSE Standards for Bereavement Care
following Pregnancy Loss and Perinatal
Death
March 2019**

FOREWORD TO PATHWAYS

Dealing with the loss of a baby or pregnancy can be a difficult and devastating time for parents and families. Parents and families may need a range of immediate and longer term supports to help them with their bereavement. There are a range of health and other support services that can play a positive and helpful role for parents during this time.

Bereavement care needs to be integrated with the hospitals' overall medical and clinical response to parents. Parents and families who experience the loss of a baby or pregnancy need appropriate care delivered in a sensitive and supportive manner. It needs to be delivered by trained staff that can assess the parents' bereavement care needs.

The purpose of this pathway is to guide health care professionals working in the Maternity Hospitals providing the care to parents who have experienced a Neo Natal Death. It is to be used to guide the healthcare professionals **what** to do for the parents- it is not intended to instruct them **how** to provide care. It is to be used to ensure that the care provided to bereaved parents is standardised throughout the country. This pathway is intended for use in conjunction with the relevant current clinical guidelines, professional codes of practice, relevant legislation and the National Standards for Bereavement Care Following Pregnancy Loss and Perinatal Death.

BREAKING BAD NEWS TO PARENTS

	YES	COMMENTS	DATE	INITIALS
Use private room when speaking to Parents about transitioning to comfort care				
Arrange Interpreter if necessary – avoid using family members as interpreters				
Discuss care and decisions with both Parents and or a support person. If Parents not married, mother has to be present				
Nurse/Midwife and Registrar caring for Baby should be present with consultant during discussion				
Ensure that other member of the multidisciplinary team are available to give Parents further information on diagnosis/ outcomes				
Document plan of care in notes as discussed with Parents				

CARE OF PARENTS AND FAMILY WHEN TRANSITIONING TO COMFORT CARE

	YES	COMMENTS	DATE	INITIALS
Utilise single room for care of Baby and family if possible.				
Explain facilities to Parents (quiet room, prayer room)				
Discuss open visiting times (for Family etc.)				
Facilitate and support visiting for siblings				
Inform Bereavement specialist CMS/CNS of Baby's condition				
Offer all bereavement support services (e.g. pastoral care, MSW)				
Allow Parents time to spend with their Baby and time to ask questions				
Ensure Parents are involved in decision making where appropriate				
Offer Parents refreshments as they may not want to leave the neonatal unit				
Provide complimentary parking where possible				

CARE OF BABY AT END OF LIFE

	YES	COMMENTS	DATE	INITIALS
Utilise single room for care of Baby and family				
Explain the specific symbol for Pregnancy Loss to Parents				
Offer Pastoral care for Blessing/naming				
Baptism performed				
Name of person who performed baptism:				
Give Parents memory box and explain how to use same				
Assist Parents to commence memory making process as soon as possible while Baby is alive				
Take / offer mementoes:	Yes <input type="checkbox"/>			
	Hand & foot prints			
	Lock of hair			
	Name Band			
	Cord Clamp			
	Memory box			
	Photographs - NILMDTS			
	Signature:		Date:	
Encourage Parents to hold and facilitate kangaroo care where possible				
Prescribe adequate analgesia (consider route i.e PO, Buccal, IV, based on access available)				

	YES	COMMENTS	DATE	INITIALS
Manage all other symptoms as per neonatologist and document in Baby's notes				
Contact/consult with palliative care team in OLCHC if necessary				

Once the decision to transition to comfort care is made, give Parents adequate time to ask questions, to have family members met their Baby, time to hold their Baby and create memories. Staff should then speak to Parents and plan removal of ventilation support in line with Parents wishes.

	YES	COMMENTS	DATE	INITIALS
Discontinue invasive monitoring and electronic monitoring once discussed with Parents				
Turn off Cardiac and saturation monitoring prior to disconnecting mechanical ventilation				
Hold all laboratory investigations unless specific bloods or tissue samples are required for diagnosis. Explain to Parents				
Allow Parents to decide who is present when the ET tube is being removed				
Ask Parents if they wish to hold Baby while ET tube is being removed				
Suction ET tube prior to removal				
Aspirate nasogastric tube if insitu and hold feeds prior to removal of ET tube				
Utilise an adhesive removal swab to ensure Baby's comfort				
Examine Baby and auscultate of the heart rate once ET tube removed and electronic and invasive monitoring has been removed				
Neonatologist or Registrar on call to pronounce death of the Baby in a sensitive manner				

CARE OF BABY FOLLOWING DEATH

BABY'S NAME				
	YES	COMMENTS	DATE	INITIALS
Give Parents time to see and hold Baby				
Offer Parents opportunity to bathe and dress Baby				
Facilitate open visiting with Family members				
Use Cuddle Cot on postnatal ward if Parents wish to have Baby with them				
Continue memory making and include all mementoes that Parents may want in memory box (i.e. sheet from incubator, cardiac leads, clean nappy, name bands, name/cot cards)				
Prepare Baby for post mortem examination i.e. paperwork/transport				
Offer Parents opportunity to include their Baby in the Hospital Book of Remembrance				

POSTNATAL CARE OF MOTHER (IF APPLICABLE)

	YES	COMMENTS	DATE	INITIALS
Use Hospital postnatal care pathway for Maternal care if mother is still an inpatient.				
Inform Bereavement CMS/CNS of Baby's death				
Offer all bereavement support services (e.g. pastoral care, MSW)				
Discuss suppression of lactation				
Consult lactation Consultant (as needed)				
Complete discharge summary				
Inform GP by faxing a copy of the discharge summary and posting the original to the surgery				
Inform Public Health Nurse				
Ensure that the Parents have all the relevant contact details for the bereavement team on discharge				
Provide information for patient advocacy support groups				
Refer for postnatal review appointment (as per Hospital policy) with Consultant – Obstetrics and Neonatology	Signature:		Date:	

POST MORTEM EXAMINATION

If a post mortem examination is directed by Law at the request of the Coroner, **no consent is required** but written information is provided to the Parents and explained sensitively.

	YES	COMMENTS	DATE	INITIALS
Offer post mortem examination to all Parents				
Give post mortem examination information				
IF PARENTS AGREE TO POST MORTEM EXAMINATION - CARE AS BELOW				
Consent:	Consent form complete			
	Signed by Parents			
	Signed by witness			
	Parents requests explicitly indicated on form			
Liaise with Pathology department re post mortem examination scheduling				
Book post mortem examination				
Date and time of post mortem examination	Date/Time:			
Place of post mortem examination	Location:			
If post mortem examination off site: name and contact number of responsible person in Pathology department	Details:			
Arrange Transport				
Transport – type				
Book Skeletal X-rays				
Skeletal X-rays completed				
Parents informed of post mortem examination arrangements				

POST MORTEM EXAMINATION (Cont'd)

	YES	COMMENTS	DATE	INITIALS
Send Consent Forms to Pathology department				
Ensure original clinical request form completed and sent				
Mother's notes to accompany Baby				
Addressograph labels for Mother				
Addressograph labels for Baby				
Specimen labels for Placenta				
Accompanying person to post mortem examination laboratory	Name			
Location of Baby: Time Baby left ward for post mortem examination	Time:			
Location of Baby: Time Baby returned to ward following post mortem examination	Time:			
IF PARENTS DECLINE POST MORTEM EXAMINATION - CARE AS BELOW				
If post mortem examination declined: Offer full examination by Neonatologist/Paediatrician/Pathologist				
Obtain consent for clinical photographs				

FUNERAL ARRANGEMENTS

	YES	COMMENTS	DATE	INITIALS
Discuss the options available for burial or cremation				
Document the arrangements decided upon				
Provide the coffin by the undertaker on contract with the Hospital				
If the Family choose Hospital burial Organise as per local policy				
If the Family choose Hospital burial Inform them of the date and time of burial and offer them the option to attend				
If the Family are arranging their own burial Give advice regarding same				
If the baby is to be cremated Complete and sign local documentation				
Explain the registration and certification process (as per local guidelines)				

DEATH CERTIFICATE & REGISTRATION

	YES	COMMENTS	DATE	INITIALS
Neonatologist must complete a death certificate				
If post mortem carried out, death certificate complete once PM results available				
If coroners case, the coroner completes the death certificate				
Inform Parents, once death certificate is completed that they can attend their local registration office to register their 's birth and death				
Give Parents contact details of local registration office				

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REVIEWERS

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