Management of Neonatal Death

Definitions of fetal loss:

| Abortion | is the loss of a fetus less than 20 weeks gestation or, if gestation cannot be reliably determined, loss of a fetus weighing less than 400 grammes at birth (NSW Department of Health, 2000). |
| Stillbirth | is the loss of a fetus who shows no signs of respiration or heart beat or other sign of life after birth and who is at least 20 weeks gestation. If gestation cannot be readily established at greater than or equal to 20 weeks, then the weight of the fetus is at least 400 grammes at birth (NSW Department of Health, 2000). |
| Neonatal Death | is the loss of a baby, who has taken a breath and / or has a heart beat after birth irrespective of gestational age but does not live past 28 days. If the child subsequently dies, it must be registered and notified to the registrar together with the cause of death in accordance with the Registration Act (1995) or, alternatively reported to the coroner (NSW Department of Health, 2000). |

For bereavement guidelines relating to the management of stillbirth and Cervagem inductions see Delivery Ward & Antenatal Midwifery Policy & Procedure Manuals

Background
Provision of a supportive and safe environment that assists the parents and family to accept the reality of perinatal death is an integral and important role of the multidisciplinary team at RPA Women & Babies. The medical officers, midwives, nurses and social workers liaise closely and share information to ensure that continuity of care and consistent information is provided to parents. The psychological impact of perinatal death on parents and families has been widely studied and now the routine yet empathetic management of perinatal grief has evolved into an individualised and compassionate ethos that attempts to meet the unique needs of each family unit. This includes respect for the emotional, cultural and religious needs of the family and significant others.

When a baby is not expected to live
Sometimes it is not in the best interests of the child to pursue intensive care, and appropriate and timely withdrawal of treatment may be considered more compassionate than continuing with aggressive measures (Penticuff, 1998; Lui, 2003). The decision to withdraw life support from the sick, extremely preterm and / or infant with congenital abnormalities is a complex and difficult decision and is stressful for both parents and the neonatal team. It is therefore essential that communication with parents remains open and honest. Information needs to be delivered in a simple and consistent way so that parents feel comfortable and empowered to ask questions and participate in the decision making process.
When an infant’s condition is known to be terminal it is essential to involve parents at all stages of the decision making process (Fox et al., 1997). Parents must be supported through the experience and the reality of loss.
**Parental choice**

Each experience of grief is unique and while rules should not be made, the midwifery and neonatal team can compassionately guide and support parents through this difficult time. Offer parents the support of the social work service (NICU social worker page 80517 / on call social worker may be contacted through switch – ext. 91). Families have individual needs and even within families, needs may be different. Choices therefore can empower parents and give some control.

Use of photographs, memorabilia such as foot prints or a lock of hair will provide parents with physical evidence of their infant’s short life (Forrest, 1989) and collection of these keepsakes may be suggested to parents. Experience has shown that some parents may at first refuse these offers but leave the situation open so you may return there again. It is important not to hurry parents through this grieving experience.

Parents should be encouraged to have as much contact with their infant as possible while he / she is still alive (Forrest, 1989). It is important for the parents to see, hold, and name their infant. The nurse should guide parents and recommend they share in their infant’s care. Opportunities for parents to parent their infant should be provided. Privacy during these intimate and cherished moments is important. When appropriate reassure parents that their infant will not feel pain as death nears but that they may change colour and their breathing may be labored and even noisy. Explore their feelings about holding, being with their baby at death.

Ensure the mother is physically comfortable, communicate with the postnatal ward midwives and ensure analgaesia is provided when appropriate. A meal / refreshments may be ordered for parents in the nursery during long vigils (ext. 57316 / 57319).

**Pastoral care / Baptism**

Offer / assist parents to contact their minister / priest / hospital chaplain and / or additional family members for additional guidance and support – see Baptism Policy. Give parents space but ensure they can call for assistance / support at any time. Keep the midwives on postnatal ward well informed of parental needs and the condition / deterioration of the infant.

There are several rooms that may be utilised at this time to promote privacy and comfort. These include single rooms on the postnatal wards, the interview and overnight rooms attached to the nursery.

**Grief reactions and coping mechanisms**

Grief is a process by which one adjusts to the loss of a close relationship. Grief reactions can be diverse and there maybe differences between the parents’ level of understanding and / or reactions to the situation. Encourage and facilitate parents to verbalise their feelings and anxieties. The team should communicate closely with the social worker to assist in the provision of consistent and clear information. Grief reactions can be influenced by a number of factors including –

- Preparedness for the bereavement
- Previous losses
Practical suggestions for the care of the family before and after death of their baby

Continue to support parents and significant others with compassion by listening, giving open and honest communication and respecting the spiritual and cultural needs of the family. Ask the parents what they want but guide them and listen to their fears and concerns.

Following certification of death by medical officer:

- privacy for the family should be provided
- the resident should notify neonatologist on duty and obstetrician or obstetric staff specialist / registrar on call
- with permission the obstetrician / neonatologist will contact the family’s general practitioner
- the midwife / nurse in charge of shift (or delegate) should notify
  - delivery ward (58444 / 58441); Birth Centre (56405); 5 East 1 (58924 / 58458); 5 East 2 (58730 / 58481) or NICU (58459 / 57413)
  - Social worker (page through switch – 91)
  - NARMU (ext 58999 / 57735 or page through switch - 91), ring 58082/ 58083 (bed allocations) & receive discharge allocation number (to be recorded in admissions book and medical progress notes)

In general the following approaches have been found to offer comfort and support to bereaved families and may be suggested by the team as options to assist their grieving.

Again gently describe to parents how their baby will look - pale, blue or mottled. If the infant has not yet died but treatment has been withdrawn and the parents wish to hold the baby while he/she is dying explain what is likely to occur – that death will be a peaceful process. Their baby's heart will usually continue beating slowly for some time after withdrawal of respiratory support and that their baby may make some sighing sounds. Always refer to the infant by name, stay with the parents, allowing them to talk about their feelings or to cry. Time with each other and without the presence of a midwife / nurse is important for some – suggest this option and
ensure they can call for support and assistance if required. The interview room, overnight room or a postnatal room may be used to facilitate this process. Ensure the family’s physical comfort. **The mother may require analgesia and rest while her partner and others may require a meal / drinks (kitchen ext.57316/57319).**

Allow the parents time with the baby for as long as they wish, the parents may also request for siblings and family/friends to be involved.

Suggest photographs are taken of their baby, these photos may include parents, siblings and significant others. If possible take some while their infant is still alive. Other memorabilia such as footprints or a wisp of hair may be taken as keepsakes for the parents. Memory booklets for this purpose are available in the delivery ward and NICU.

In consultation and when the family is ready the infant is usually washed, removing tapes and traces of sticking plaster from the infant’s face. Some parents like to participate in this process, others do not, always offer choices and assist parents with their wishes. Ask the parents if they wish to have their baby dressed. The infant can be dressed in nappy, singlet, nightgown, hat and booties. Parents may have special clothing they would like to dress their baby in. Hand made baby clothes for viewing is kept in the storage area (NICU). Blankets of love quilts and the wicker basket are also kept in the storage area (NICU).

There are two cold drawers in consulting room three (delivery ward) that can be used until the parents are ready to relinquish the body of their infant. Please ensure the infant has correct identification tags in situ at all times. If parents request to see and hold their infant, again describe how their baby will look (blue / white) and feel (cold).

Once the parents no longer wish to see their infant the porters may be contacted (switch – 91) to transport the infant to the mortuary. The nurse must accompany the porter to consulting room three to ensure the correct infant is transferred to the morgue. **The porter is not to access the cold drawers without the supervision of a neonatal nurse / midwife.** If the porter has not arrived by the end of the shift, re page and notify oncoming midwife / nurse in charge of shift. A midwife or nurse must check the infant’s identification before the porter leaves the department.
Before sending the infant to the mortuary

- The infant should be bathed and dressed with nappy insitu, clothes provided by the parents may be used.

- The infant’s bare weigh, length and head circumference should be recorded.

- Ensure that a Newborn Screening Test (NBST) has been taken and sent to the Newborn Screening Program at Westmead (usually done on day 4). If NBST has not been taken then complete newborn screening card, take sample and send. State on card that the baby was a neonatal death.

- Ensure two ID bands are on the baby.

- A toy, religious medals etc. may go with the baby if parents wish. The item must be labeled and a note made on the mortuary cards.

- Three mortuary cards should be completed in full. If the baby has an infectious disease this is also documented on the mortuary cards. One is attached to the infant’s wrist. DO NOT USE PINS. The other is attached to the zipper pull on the mortuary bag. The third card is attached to the mortuary bag and will be used by the mortuary attendant to assist identification of infant while in the morgue.

- Place the baby in the body bag with the infant’s head at the closure end of the bag.

- Using a black waterproof marker, write the patient details (copy from the mortuary card) on the top left-hand corner of the bag. If the baby is infectious also write "Infectious disease handle with care".

For further information about the management of the infant with an infectious disease refer to the RPA Nursing Procedure Manual (section 15.5 Post Mortem Procedures). This section documents the infectious diseases that require documentation and the correct procedure for labeling and sealing body bags.
**Transport of the baby home**

Some parents may request to take their infant home after death, this is an option and the social worker should be contacted to discuss legal requirements and provide additional information. The Public Health Regulations state that a deceased is not to remain un-refrigerated for longer than 8 hours in any one-day. Dry ice is to be organised before the baby can be discharged, and contact details of the funeral service the family will be using to collect the baby from home is needed for our records. The social work department is to be contacted in all instances should the family wish to take the baby home, after death. Some contra indications to this may include infectious disease and consent for post mortem.

**Coroner’s case**

The need for a coroner’s investigation is rare following perinatal events. If the decision is made to notify the coroner’s office following an infant’s death, notify NARMU and consult the *RPA Nursing Policy Manual (section 15.5 Post Mortem Procedures)* for further details on preparation of the body. In this event the body should not be washed but may be cleaned for viewing by the parents – seek advice from the consultant neonatologist before removing lines or endotracheal tube.

**Consent for postmortem and chromosome studies**

This is the responsibility of the senior medical officers and should be considered following an unexpected intra uterine death or where a fetal abnormality may impact on subsequent pregnancies. It is important that the midwifery / nursing team provide support for the post mortem process, experience suggests that parents often regret a decision not to proceed with post mortem. The investigations may provide information about the cause of death, assist parents with their grief and assist the planing of future pregnancies (Forrest, 1989). This is a painful decision for parents and it is therefore crucial that parents are informed of the results as soon as practical by the consultant obstetrician / neonatologist who can interpret the findings and make recommendations about future perinatal management and / or refer the family for genetic counseling. Presence of the social worker at these interviews is important to assist the family with bereavement and other issues.
**Nursing documentation after death** - all forms are kept in the Angel Folder at the nurses’ station **NICU**

<table>
<thead>
<tr>
<th>Description</th>
<th>Details</th>
</tr>
</thead>
<tbody>
<tr>
<td>The midwifery / nursing report (progress notes)</td>
<td>Documentation should include the time of death, comfort measures, bereavement plan agreed with parents, parental reactions and coping mechanisms. The time and date the infant’s body was picked up by the porters should be recorded in progress notes.</td>
</tr>
<tr>
<td>Mortuary book</td>
<td>NICU nurses to complete book when infant’s body is transferred to morgue</td>
</tr>
<tr>
<td>Baptism book</td>
<td>Complete when appropriate – see Baptism policy</td>
</tr>
<tr>
<td>OIS</td>
<td>Discharge summary reports (3) should be printed to stay in the baby’s notes. If the mother has been discharged a copy of her discharge summary should be printed and left in the notes.</td>
</tr>
<tr>
<td>Document in progress notes that personal items have been given to parents or have accompanied infant to the morgue</td>
<td>Ensure parents receive any personal items such as their baby’s clothing, the blanket of love, other memorabilia, toys or possessions as these are often of great importance to parents and provide some tangible evidence of their infant’s short life.</td>
</tr>
<tr>
<td>Notification of Death Form (pink)</td>
<td>One copy to be sent to nursing administration, 1 copy to the front desk and 1 copy should remain in the notes. <em>Extension 58964 should not be called as this is the number for cornea donations and is not applicable to infants.</em></td>
</tr>
<tr>
<td>X ray request form</td>
<td>If ordered by neonatologist this form is to accompany the baby (tell porter) and the radiographer should be notified by phone or page – (8.30 - 4.30 Mon to Fri: contact X-ray – 58915 / after hours 4.30pm - 8.30am: ring 58915 or page 81082).</td>
</tr>
<tr>
<td>Infant’s medical record</td>
<td>The ward clerk will deliver notes to the Medical Record Department (Level 4 East). Once parental consent for post mortem is obtained remind medical officer to contact duty pathologist.</td>
</tr>
<tr>
<td></td>
<td>Post Mortem &amp; consultation forms may be faxed by medical officer to Anatomical Pathology ext 58405 (leave original forms with infant’s notes).</td>
</tr>
</tbody>
</table>
Medical documentation after death - the following documentation is the responsibility of the medical officers. This information is provided here to ensure nothing is overlooked.

<table>
<thead>
<tr>
<th>Consent for Postmortem</th>
<th>If a postmortem has been consented then this form must be completed with the parents signature. If autopsy is not going to be attended the form still must be completed by medical staff and the words Not For Autopsy written across it. This form stays in the infant’s notes.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Attending Practitioner Cremation Certificate</td>
<td>This form must be completed regardless of whether it is known if the baby is to be cremated.</td>
</tr>
<tr>
<td>Notification of Death Form</td>
<td>Form to be completed in full and signed by attending medical officer</td>
</tr>
</tbody>
</table>
| Medical Certificate for Cause of Death Perinatal Book | Triplicate form  
  - White copy goes with notes to medical record department (used to produce official death certificate / stays in infant’s notes as a permanent record)  
  - Green copy with notes to medical records (funeral director’s copy)  
  - Blue copy this copy is filed by ward clerk in the Angel Folder (this form will be eventually sent to medical records after M&M peer review). |

All these forms plus the OIS Record of Labour and Summary of Baby are taken to the medico-legal section of the Medical Record Department and signed for (insert signed form back into the Angel Folder).

Advice regarding suppression of lactation
The mother may need advice regarding her lactation. Please refer to the CSAHS and / or NICU Breast Feeding Policies and reassure her that although suppression of lactation with medication is not recommended comfort can be achieved. After discharge the Lactation team is available for advice for additional support and advice and mothers may contact team via RPAH switch.

Death registration and funeral arrangements
It is helpful if in addition to the social worker, nurses and midwives are aware of the legal procedures and funeral arrangements when an infant dies. This can serve to alleviate a great
deal of anxiety for those parents who have not experienced a previous loss in their immediate family. Funerals also incur some expense therefore parents should be encouraged to discuss any financial concerns with the social worker, who can advise them of any potential entitlements.

**Follow up**

Sensitive and supportive follow up is important for all families with a perinatal loss. At RPA Women and Babies, this is provided by the social worker department. The parents will be offered a follow up meeting with the social worker and obstetrician / neonatologist at six week. Two studies (Forrest, 1982, Lake, 1987) have observed that socially isolated women and woman with low levels of social support tend to have a higher incidence of long term morbidity following perinatal loss. Another trial (Lilford, 1994) also suggested that women who had a termination of pregnancy for fetal anomalies had slightly worse outcomes than those women who experienced a stillbirth or neonatal death. Consideration should be given to an increased level of support for those families at increased risk.

**Parent support groups**

RPA Women and Babies Social Work Department run a SIDS (SANDS) Support Group monthly. This is a support group for families who have suffered pregnancy loss, stillbirth and neonatal death. The group is run on the first Tuesday of every month, 7-9pm in the Professorial Room, Level 5, RPA Women and Babies Executive Unit. Enquiries to Sara Burrett ph 9515 7567.

**Support for members of the perinatal team**

All members of the perinatal team may need additional support and debriefing at some time. Guiding and supporting a family during perinatal loss can be a difficult and emotionally draining experience. This is one such time when the perinatal team needs to be cohesive and sensitive to their colleagues’ need. Debriefing sessions and / or opportunities to talk with a trusted peer can facilitate a nurturing and supportive team and work environment.

**References**


