CHILDREN’S SERVICES

NEONATAL INTENSIVE CARE UNIT

GUIDELINES TO FOLLOW IN THE EVENT OF A DEATH OCCURRING ON THE NEONATAL INTENSIVE CARE UNIT

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GUIDELINES TO FOLLOW IN THE EVENT OF A DEATH OCCURRING ON THE NEONATAL INTENSIVE CARE UNIT

See also:

Guidelines in the Event of Parents Requesting to Take Their Deceased Baby Home (post 24 weeks)
Mortuary Viewing Policy and Procedure
Early Release of the Deceased Patient Out of Normal Working Hours
Last Office Nursing Procedure

Definitions of Death:

A sudden/ unexpected neonatal death is a live born infant regardless of gestational age who dies within 28 days of birth. On the neonatal unit this may occur anytime following admission.

A baby may also die on the neonatal unit after 28 days of life and will require slightly different documentation i.e. a different Medical Cause of Death Certificate. There is one book for the death of a baby up to and including 28 days and another book for the death of a baby after 28 days of life.

All procedures however, would be the same as for the death of a baby before 28 days. Therefore, this policy is to be used in the death of a baby of any age.

It is extremely important to complete the Checklist for a Death on NICU (Appendix 1).

Please also follow the Pathway for a Death on NICU (Appendix 2). These are aimed at helping the nurse and doctor follow the correct procedure and ensuring that the parents receive all the information needed at this time.

It doesn’t necessarily matter in which order many of the procedures are done as this will very much depend on the needs of the parents at the time. However, it is important that all steps are completed.

These guidelines exist to further support the staff in any area of uncertainty. It is arranged so that each item of the Pathway has a corresponding paragraph in the Guidelines.

The Checklist (Appendix 1) and Pathway (Appendix 2), together with all forms that may be needed following a death on the Neonatal Unit are kept in prepared packs. These are in the purple folder in the bereavement trolley on the NICU. These guidelines are also available on the bereavement trolley and Intranet for clarification when needed.

There are two different packs available – one contains all paperwork needed after a Death on NICU. The second pack contains all paperwork needed if a Post Mortem is requested.
**The Bereavement Packs** contain:

1. Checklist (Appendix 1)
2. Pathway (Appendix 2)
3. Medical Certificate (Cremation Form)
4. Form A Notification of Child Death
5. Perinatal Mortality Information Form
6. Mortuary Admission Form
7. Directions to Weybridge Registrar’s Office
8. Bounty Mailing Suppression Request
9. White envelope (for Medical Cause of Death Certificate)
10. Envelope containing - Caring booklet (SANDS)
    - Memories booklet (SANDS)
    - Various information leaflets
11. Bereavement Follow-Up Form
12. Parent Information Following the Death of Your Baby on NICU
13. NICU Counselling Service Patient Information Leaflet
14. Feedback Form

**The Post Mortem Packs** contain:

1. Consent to a Hospital Post Mortem Examination on a Baby or Child
2. A Guide to the Post Mortem Examination Procedure Involving a Baby or Child
3. Perinatal Post Mortem Request Form
4. Information for parents about Post Mortem Examination of babies and children at St George’s Hospital

Also on the Bereavement Trolley are the:

- Notice of Death book
- Medical Cause of Death Certificate – less than 28 days of age
- Medical Cause of Death Certificate – more than 28 days of age
- Referral to Bereavement Office (previously known as Patient Affairs)
- Register of Baptism Forms
1. Commence Checklist (Appendix 1)

A Checklist for a Death on NICU (Appendix 1) is available and must be completed for all deaths. It is a fairly comprehensive list and is meant to serve as a trigger for action. Please make sure this is filled in as this will ensure that all necessary documentation is completed and everyone is informed appropriately. ALL items must be ticked either yes or no. If ticked no, please give reason.

2. Discuss with parents the options regarding their involvement in the care of their baby

As with all bereavements, individuals react in different ways. It is also important to bear in mind that the mother and father will probably have different needs. A little bit of extra effort will aim to support both parents through their loss. They may want to be totally involved with taking photographs and footprints, bathing and dressing their baby or they may prefer you to take the baby away and do these things for them. Whatever they want is right for them! Don’t forget that one parent may wish to be very involved while the other may prefer not to be present. We should aim to cater for the needs of both parents.

Always remember to give them choices because unless you do, they will not know what choices they have. When you are giving parents choices it is also important to then give them time to make their decisions. It is also essential that the choices made by the parents are then respected by the health professionals. Let them know that it is also acceptable for them to change their minds.

The experiences of parents at this stage can have a lifelong effect on the length and severity of the grieving process (Thomas, 2001).

If requested, it may also be possible for parents to take their baby home. The Bereavement Office will help arrange this but out of hours the Site Co-ordinator would need to be contacted. Refer to Guidelines in the Event of Parents Requesting to Take Their Deceased Baby Home (post 24 weeks) and Policy for Early Release of the Deceased Patient Out of Normal Working Hours. ALL paperwork would have to be completed first. The Mortuary Technician would need to be contacted by telephone and all paperwork would need to be faxed to the mortuary prior to the baby being released.

3. Is further bereavement support required?

The parents may need further support either now or in the future. They may want other family members present, or the hospital Chaplain (contact via switchboard) is also an excellent source of support if required. She is also able to give advice about different religions and faiths if needed. Alternatively, they may prefer privacy.

The NICU Bereavement Support Nurse may be contacted (ext 3889). Other sources of support are SANDS, Child Bereavement Trust, Bliss and Cruse.

It is also important to remember that the Nurse and/or Doctor may also require support now or later. It is ok to ask!

4. Would parents’ like their baby blessed?

A baptism may not be possible if baby has already died but the parents may like a blessing, a naming ceremony or even a simple prayer. If they do then the Chaplain should be contacted as soon as possible.
Religious and/or cultural beliefs should be acknowledged and religious and spiritual support is always available, whatever time of day or night. Some parents may prefer to see their own priest or religious leader. The Chaplain is available to help contact them if needed. There is a file containing information on different cultural issues and contact numbers. This is a very useful resource that has been compiled by the hospital Chaplain and can be found on the bereavement trolley.

The hospital Chaplains should be paged via switchboard and are on call 24 hours a day.

The parents may or may not wish to be present and they may also like other family members with them for this special service. Again, whatever the parents need. Give them choices.

Parents will be given a certificate as a record of their baby’s baptism or blessing.

5. Discuss whether post mortem is required

If a post mortem is requested then all paperwork needed is kept in prepared packs in the purple folder on the bereavement trolley.

A post mortem is a medical examination of a baby carried out by a pathologist. There are two types of post mortem – a Coroner’s post mortem or a hospital post mortem. A Coroner’s post mortem will be ordered if baby’s death was suspicious or of unknown cause. Although consent from parents is not required in this situation it is important to involve the parents fully. A hospital post mortem can be requested either by the Consultant or the parents if more information is needed and written consent will be required.

It is the doctor’s responsibility to obtain consent, and this is usually done by a Consultant. Anyone taking consent must have completed the Trust Training tracker Module “Seeking Consent for a Hospital Post Mortem”. There is an additional module “Paediatrics: Parents and Postmortems” which may also be useful. There is a booklet entitled ‘A guide to the post mortem examination procedure involving a baby or child’. These are in the post mortem packs. Ensure that parents have been given this information prior to consent being obtained as it contains a full explanation of the procedure. Sometimes parents do not wish a full post mortem examination of their baby and a limited post mortem can be offered, unless the death has been referred to the coroner.

Parents should be reassured that when a post mortem is being performed, their baby will be treated with the greatest of respect.

The Perinatal Post Mortem Request Form also needs completing by the Doctor for ALL cases sent for post mortem. This consent form and the Post Mortem Request Form should be sent with the baby to the mortuary and a copy placed in the baby’s notes.

Once the baby is in the Mortuary, transport will have to be arranged to St George’s Hospital. This is organised by the Bereavement Office. It is important that they are informed as soon as possible if there is to be a Post Mortem as transport takes a while to organise. It is acceptable in this case to leave a message on the Bereavement Office answerphone stating the baby’s details and when the baby will be ready for collection.
6. Discuss funeral options
Do parents want a burial or cremation? This may be difficult for parents to decide at this time. If there is any possibility of a cremation being required then it is important to get the Medical Certificate (Cremation Form) completed as soon as possible. If it is not needed later then that is not a problem but if parents later decide that they would like a cremation and this form has not been completed then it may delay the funeral and therefore cause more distress.

Firstly they will need to register the death. To do this they will need the Medical Cause of Death Certificate. This must be given directly to the parents sealed in the white envelope provided. When they have registered the death, they will be given a Burial Authorisation Certificate. This Burial Authorisation Certificate should then be taken by the parents to their chosen Funeral Director who is arranging the burial or cremation.

If they prefer a burial there will usually be a charge for a burial plot which is levied by the Local Authority. These vary from cemetery to cemetery. Some crematoriums are also charging a fee although this may depend on the time of the cremation.

The contract Funeral Directors used by ASPH are Alan Greenwood & Sons. Parents are able to go directly to them at:

66 Send Road, Send, Woking, GU23 7EU
Telephone 01483 210222.
Hours 09.00 to 16.45 Monday to Friday.

However, parents can go to any Funeral Director of their choice,

Normally, Funeral Directors will contact a local priest or religious leader to conduct the service unless the parents have a particular person they would like to conduct the service. If the Hospital Chaplain is suggested she will be happy to conduct the service free of charge. Other ministers may or may not charge a fee.

Some parents choose to provide flowers for their baby and this can be very helpful for them. They will however, have to cover the cost of the flowers themselves and a single flower or posy can be all that is necessary. Similarly, some parents like to have a rose bush or something similar placed at the crematorium in memory of their baby. They will need to make their own arrangements with the crematorium staff and will have to meet the cost themselves.

If the mother receives Social Security benefit from the DSS she may be entitled to having the full cost of the funeral paid for eg. cremation or a plot for burial, flowers, extra cars etc. Further details are in the Parent Information Following the Death of Your Baby on NICU leaflet.

7. Remove all long lines, cannulas, ETT, etc. (after confirming with Consultant)
Check with the Consultant that it is not necessary to leave any lines in situ once the baby has died. Whether these lines are removed before or after the parents have held their baby will very much depend on the circumstances at the time. If they held their baby as he/she died then they may like to hold their baby again once all lines have been removed. It may well be the first time they have held them without any tubes etc. in. Small plasters may need to be placed over cannula sites to prevent leakage.
The only time these lines must remain in situ is when the death is to be referred to a Coroner. This would be if the cause of death is unknown or suspicious.

8. **Give baby to parents to cuddle**

Parents should be encouraged to hold their baby. This has been shown to help with the grieving process in the long term (Child Bereavement Trust, 2000). They should be given privacy and as much time as they need. They may also wish other family members and siblings to be present.

If parents have other children they often worry about involving them for fear of them being upset. However, research in siblings has shown that their involvement in this process is also beneficial (Child Bereavement Trust, 2000). It can help to discuss this with the parents. Again, children are individual and, as with adults, may well react in different ways.

It is sometimes possible to enlist the help of a play specialist from the childrens’ ward to help with siblings if there is no family member available or if they do not wish to be present, otherwise a place in the hospital crèche may occasionally be possible.

Parents may like to stay in the nursery where baby has died or they may prefer to take their baby to the parents’ accommodation. If there are other parents resident in the accommodation it would be acceptable to ask them to leave and let the grieving family have as much privacy as they need.

If they prefer to stay in the nursery then it will need to be explained to them that the other babies will be having procedures done. Again, other parents are usually very understanding if asked not to visit for a few hours. In this environment, the time that they spend in privacy with their baby will be more limited.

9. **Confirm death**

When you think baby has died you can ask the Doctor to pronounce death. They will listen to the heart for one minute to ensure it is no longer beating. They must then document the time and cause of death in the baby’s notes.

10. **Create memories booklet**

With verbal consent of parents, take photographs in a sensitive manner. These may be of baby dressed or naked, in parent’s arms, holding hands, in the bath or in the moses basket. This may also be the only opportunity for photographs with siblings.

If parents say they do not want any photographs, ensure that you ask if you can take a couple of photographs to place in their baby’s notes as some mothers change their minds later. It should then be stressed that they will be kept safely in the notes and should they wish them at a later date they will always be available for them.

Also ask permission before taking a lock of hair. If parents consent, ensure it is taken from the back of the head where it will not show. When taking hand and footprints ensure you take a print of both hands and both feet if possible. This has been shown to be very important to parents later (Child Bereavement Trust, 2000). Ensure the ink is washed off thoroughly. An alcowipe is effective.
The Neonatal Unit provides a disposable camera if required which is kept on the bereavement trolley. This can be given to parents to take their own photos or you can take photos for them. They can then take the camera with them to have developed at a later date. Please ensure any digital photographs taken are deleted from disc.

Ask if the parents would like mementos such as their baby’s ventilator hat or the quilt that they were laying on in their incubator, cot card, name bands, ECG leads, sats probe and posey wrap. These will all provide memories of their precious baby.

11. Bath baby
The parents may wish to do this either alone or with the help of the nurse. However, some will prefer that you take the baby away and bath him/her. Give them the choice.

12. Dress baby in clean nappy and clothes
Again this may be the parents or the nurse doing this. If parents do not want to dress the baby they may still want to choose the clothes.

13. Place name bands on wrist and ankle
Babies taken to the Mortuary must be properly identified as per Last Offices Nursing Procedure. This requires that identity bands are in place on both the wrist and ankle.

14. Give parents as long as they want with their baby
Under no circumstances must parents be hurried during this process. It is important to be aware of whether they need or want the support of a nurse, doctor, other family members, or whether they want to be on their own. If unsure ask. Give them choices (CBT, 2004).

The only occasion when time may possibly be limited is if a post mortem is requested. If a post mortem is not required then it may be possible to take baby home if parents wish (Refer to Early Release of the Deceased Patient Out of Normal Working Hours Policy and Guidelines in the Event of Parents Requesting to Take Their Deceased Baby Home: post 24 weeks).

15. When parents are ready to say ‘goodbye’
When parents are ready to say goodbye, you need to be very sensitive to their needs. They may want you to take the baby from them or they may want to leave the NICU first. Parents usually feel comforted to know that you will be carrying their baby to the hospital Mortuary.

Ensure parents have been given all the information needed as per the Checklist (Appendix 1 and 2).

After ensuring baby is not left alone the nurse should walk parents either to the lift, or if possible to their car. Let them know that they can return to the Neonatal Unit to see staff or the counsellor in the weeks following their baby’s death if they would find it helpful. Some parents find it a comfort to visit but others find it unbearable.

16. Attach 1st copy of Notice of Death to clothing
Attach the 1st copy of the Notice of Death directly on to baby’s clothing.

17. Wrap baby in shawl and attach 2nd copy of Notice of Death to shawl
Wrap the baby in a pretty shawl. There is no need to cover the baby's face. Attach the 2nd copy of the Notice of Death securely to the outside of the baby's shawl.

18. Place baby in Moses basket
Baby can be placed in the Moses basket or can be carried in your arms. A bonnet and a hand discretely covering baby's face will shield them from any onlookers. However, once baby is placed in the fridge, please ensure at this stage that their face has been covered. If baby is taken to the Mortuary in our Moses basket, please ensure you bring the Moses basket back with you.

19. Ensure all documentation required is completed as per Checklist (Appendix 1)
Following the Checklist (Appendix 1) will ensure that all necessary documentation is completed prior to baby being transferred to the Mortuary. This includes the Mortuary Admission Form, the Notice of Death Certificate and the Medical Certificate (Cremation Form).

When all essential paperwork is completed then baby may be taken to the Mortuary.

20. Request a porter to escort baby and nurse to mortuary
Telephone the porter and request a porter to escort baby and a nurse to the Mortuary. This should be within 2 hours of parents leaving and the request will also need to be actioned via PAS.

If the nurse is uncomfortable going to the Mortuary then this should be respected. However, a member of staff should accompany the baby so it would be necessary to find a colleague who is willing to complete this task. If the baby is ready to go to the Mortuary at night, it is acceptable to wait until the morning if preferred. Labour Ward have a fridge for storage of baby meanwhile. Ensure that baby's face is covered, their name is written in the book on the fridge and that Labour Ward shift leader is informed. Also please remember to hand over care at the end of your shift. Care and responsibility of baby does not finish until baby is in the mortuary.

The porter will come up to the NICU and the nurse will carry the baby and be escorted by the porter to the mortuary. On admission to the Mortuary the porter will complete all necessary paperwork. The nurse will then return to the NICU and complete all remaining documentation.

Viewing is possible at the mortuary, but it is preferable to advise relatives to view through the Funeral Directors at their Chapel of Rest. If parents want to have a viewing at the hospital Mortuary then an appointment needs to be made. This must be made through the Bereavement Office during office hours and will usually only be in the afternoons. These are Mon – Thurs 09.00 to 12.30, Fri 09.00 to 15.00. Out of these hours, viewing may be possible in exceptional circumstances and would need to be arranged via the site coordinator as per the Mortuary Viewing Procedure.
21. DOCUMENTATION

It is essential that documentation is completed accurately in order to minimise further distress to parents.

PLEASE ENSURE BOTH PARENTS SURNAMES, IF DIFFERENT, ARE WRITTEN ON ALL FORMS

The Medical Cause of Death Certificate, Death Notice and Medical Certificate (Cremation Form) will be needed urgently

21.1 The Doctor who was in attendance at the time of death must complete the Medical Cause of Death Certificate as soon as possible following the death. This is needed for the parents to register the death. The correct book must be used. There is one book for a baby dying at less than and including 28 days of age and another book for babies more than 28 days of age at time of death. If the baby is 28 days on the day of death, then the book for less than 28 days must be used.

When completing this form the Doctor should first discuss this with the Consultant. They must not use abbreviations and should print their name under their signature. They should ensure the form is completed legibly because if the Registrar of Deaths cannot read it they will not register the death. Please complete using surname of both parents and then write the cause of death in the baby’s notes.

This completed Medical Cause of Death Certificate is then placed in the white envelope that is provided in the bereavement pack and sealed. It is helpful if the name of the baby and the name of the Doctor who has signed the certificate is clearly printed on the outside of the envelope. This envelope must then be given directly to parents.

21.2 The Medical Certificate (Cremation Form) must be completed as soon as possible if parents would like their baby cremated. This should ideally be before the baby leaves NICU to go to the Mortuary. Please complete using the surnames of both parents. The form comprises of Cremation 4 (replacing Form B) and Cremation 5 (replacing Form C). Crem 4 must be completed by the Registrar or Consultant present at the time of death. If the Doctor is not going to be on duty in the 24 – 48 hours following the death and completion of the Cremation Form, ensure they leave a contact number or ask a colleague to complete the form. This is because the Doctor completing Crem 5 has to be able to speak to the Doctor completing Crem 4.

Crem 5 is to be completed by an independent senior Doctor with not less than 5 years post registration qualification, from a separate medical team. If this is a problem the Bereavement Office may be able to get a doctor to complete this form. If in doubt ask the Bereavement Office.

The Doctor completing Crem 5 needs to see the baby. Please ensure each question is read carefully and answered accurately.
If a Post Mortem is to take place then only the first part of the Cremation Form (Crem 4), can be completed. The Pathologist will then complete the second part (Crem 5).

If this form is not completed correctly the cremation may be delayed thus causing unnecessary aggravation and anguish.

21.3 Form A Notification of Child Death needs to be completed as soon as possible and not later than the next working day. The responsibility for completing the form lies with the Consultant on call at the time of death, but can be delegated to any member of staff. Please complete using surnames of both parents. After completion it needs to be faxed to the relevant office, this will be Linda King if baby from Surrey area but if out of area then may need to be sent to the relevant office. The Co-ordinator will advise. When faxing, the number is on the top of the Form A, please phone the Co-ordinator first to let her know it is coming and ensure that all 5 sides are sent. Place the original in the baby’s notes.

Notes on completion: Pg 1 Name of referrer = Consultants name
Pg 3 – Usually parents and close family members who have been involved in care
Pg 4 – Paediatrician – the baby’s Consultant, not necessarily the one on-call and completing the form

21.4 The Notification of Death Form must be completed. The 1st copy is attached to the baby’s clothing and the 2nd copy is attached to the baby’s shawl when taking to the mortuary. The 3rd copy is sent to the Bereavement Office and the 4th copy remains in the book.

21.5 Complete a Hospital Mortuary Admission Form
This accompanies baby to the Mortuary. Remember to record on this form any toys, blankets or other memento’s that have gone to the Mortuary with the baby.

21.6a The Post Mortem Consent Form. If requested by the Consultant on the Neonatal Unit or the parents, then the Doctors are required to obtain consent and complete this form. On the Neonatal Unit this would usually be the Consultant. Ensure the guide to post mortem examination on a baby or child is given to parents prior to this form being signed.

Once consent has been signed one copy of the completed form should be given to the parents, one copy placed in the baby’s notes and the original accompanies the baby to the Mortuary.

21.6b The Perinatal Post Mortem Request Form will also need to be completed by the Doctor and accompany baby to the Mortuary. Take a copy of this form and place in baby’s notes.

21.7 Complete and send the Perinatal Mortality Information Form to the Maternity Unit Reception.

21.8 Complete the Bounty Mailing Suppression Request Form. Ensure the already distressed mother does not receive any mailings from Bounty by completing this form. Place this in the box on Joan Booker Ward for collection by the Bounty Representative.
21.9 Fill in baby’s and parents details on the **Bereavement Follow-Up Form** and place in baby’s notes. Any further information can be completed that you feel may be relevant during follow-up. This will ensure the family receive appropriate follow up. Families leaving the Neonatal Unit after the death of their baby deserve and need the same level of follow-up as those taking a live baby home *(Carroll et al, 2002)*.

21.10 Enter ‘deceased’ in the **ward admission book**, together with the date.

21.11 Complete a **Referral to Bereavement Office Form (previously Patient Affairs)**. This must be taken **by hand** to the Bereavement Office as soon as possible.

22. **Parents will need to register the baby’s death (and birth)**
   Explain to parents that they will need to register their baby’s death.

   The parents must also **register the birth** of the baby if this has not yet been done. If they are unmarried it is the mother who must do this. The mother or father must also **register the death** of the baby. This must be done by law within 5 working days and can be done by either parent regardless of marital status. The parents will need to take the Medical Cause of Death Certificate with them.

   The parents will need to telephone and make an appointment first. If they inform the Register Office that they will be coming to register their baby’s birth and death they will ensure that the parents are seen promptly and without them having to sit in the main reception area with other parents who may be registering births.

   The details of St Peter’s Hospital Registrar is:

   81 Oatlands Drive, Weybridge, Surrey, KT13 9LN
   Telephone: 08456 009009 – centralised system
   Hours: Mon – Fri 09.00 to 16.30 Wed 09.30 to 16.30

   Deaths at St Peter’s Hospital should usually be registered at Weybridge. However, if the baby was transferred from another hospital then it is possible for the parents to register the death **BY DECLARATION** at their local Register Office. This will however cause some delay in the baby being released to the Funeral Directors.

23. **Ensure memory box and completed memories book is given to parents**
   If the parents wish, give them any photographs and prints that were taken, together with any other mementos. These can be given to them in one of our specially made memory boxes.

   The Parent Information Following the Death of Your Baby on NICU leaflet provides all the information needed for parents on what they need to do. Please also ensure all **appropriate** and **relevant** information leaflets are given to the parents. There is a selection available in each of the prepared packs on the bereavement trolley. If unsure, as long as you document which leaflets have been given, then any other relevant leaflets can be given to the parents later at follow-up.
A booklet about all aspects of neonatal death, published by SANDS (The Stillbirth and Neonatal Death Society) is available to give to all parents. The parents may find the information in this booklet helpful in enabling them to come to terms with their loss and in coping with their feelings. All forms, together with SANDS booklets that may be needed are kept in packs in bereavement packs in the purple folder on the bereavement trolley in the Neonatal Unit.

Also ensure parents are aware that there is a Remembrance Book available. They may wish to make an entry at a future date. This is kept on the NICU and can be viewed at any time.

The hospital holds an annual Remembrance Ceremony for children who die at any age from early pregnancy to adulthood. This is usually in June and all parents will be sent an invitation.

24. Ensure all necessary personnel informed
Ensure all personnel on the checklist (Appendix 1) are informed.

This includes the following:

- The Consultant will usually be present at the time of baby’s death, if not, he/she needs to be informed. If the baby has been transferred from another hospital it will be necessary to inform the referring Consultant/Neonatal Unit.
- The Bereavement Office must be informed of baby’s death. If the death occurred out of office hours then this is the only department that it is acceptable to leave a message on the answerphone. It is helpful for them to be aware of the death as soon as possible.
- If Mum is still on Labour Ward or Joan Booker Ward ensure the Midwife looking after her is aware of the situation.
- If baby is less than 28 days old at time of death then inform the Community Midwife.
- Ensure the GP is informed. Although this is the Doctor’s responsibility please make sure this is done.
- Notify the Birth Clerk at Goldsworth Park Health Clinic. The clerk will notify the relevant child health office if the baby is from out of area.
- If the baby was one of a twin or higher multiple birth, please inform the Parent Education Co-ordinators.

25. Complete documentation in baby’s notes
Ensure date, time and cause of death have been written in the baby’s notes.

25. Discharge baby on PAS
The baby must be discharged from PAS. A message can be left for the ward clerk to do this, which will automatically cancel any future outpatient appointments they may have. It is very distressing for relatives to receive appointments for someone after they have died.

26. Leave baby’s notes with instructions to go to Consultant’s secretary
The Consultant’s secretary will offer an outpatient appointment for 4 – 6 weeks for the parents. This is an opportunity to discuss any outstanding issues or questions they may have following the death of their baby. Not all parents wish to take this up.
27. Staff Support
It is important to support staff when caring for dying babies and their families, as this may raise moral, religious or ethical dilemmas for the individual. Remember junior staff, both doctors and nurses, may never have experienced the death of a baby before. Also senior staff on the other hand may have dealt with many deaths, but it is never easy!

“The need for support is not a sign of professional inadequacy or personal weakness, but rather a sign of maturity, recognizing that you need help to do this work well. Most professional carers are very good at caring for others, but far less good at caring for themselves or for each other. If you know that one of your colleagues is involved in some stressful work, try to find the time to listen to them and how they feel afterwards. It can make an enormous difference to have a colleague that cares about you. This is no less important if you are a consultant or a manager”.

CBT (2000)

Support may be from colleagues, your manager, Hospital Chaplain or NICU Bereavement Support Nurse. The CBT also has an information and support line for professionals on 0845 357 1000 and the Trust Employee Assistance Programme can be contacted on 0800 282193.
DEATH OCCURRING ON THE NICU

REFERENCE LIST / BIBLIOGRAPHY

References:


Ashford and St Peter’s Hospitals (undated) *Caring for Bereaved Parents – Information for Midwives, Nursing Staff and Care Assistants*. Dept of pastoral Care: St Peter’s Hospital Chaplaincy

Ashford and St Peter’s Hospitals (Sept, 2000) *Mortuary Viewing Procedure*. Issue 2


Bibliography:


**CHECKLIST FOR DEATH ON NICU - APPENDIX 1**

(This checklist is to be used in conjunction with pathway and guidelines)

PLEASE COMPLETE DOCUMENTATION WITH BOTH SURNAMES (IF DIFFERENT)

<table>
<thead>
<tr>
<th>BABY’S NAME</th>
<th>HOSPITAL NO.</th>
<th>DATE OF DEATH</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
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</table>

<table>
<thead>
<tr>
<th>PARENTS NAMES</th>
</tr>
</thead>
<tbody>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>FORMS TO BE COMPLETED</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 Medical Cause of Death Certificate</td>
</tr>
<tr>
<td>2 Medical Certificate (if cremation required) (send to Bereavement Office)</td>
</tr>
<tr>
<td>3 Form A Notification of Child Death</td>
</tr>
<tr>
<td>4 Notice of Death x1 copy to remain in book x1 copy to Bereavement Office x2 copies to accompany baby</td>
</tr>
<tr>
<td>5 Mortuary Admission Form</td>
</tr>
<tr>
<td>6 Is Post Mortem required?</td>
</tr>
<tr>
<td>IF YES:</td>
</tr>
<tr>
<td>a A Guide to Post Mortem Examination given to parents</td>
</tr>
<tr>
<td>b Consent to Post Mortem Examination signed</td>
</tr>
<tr>
<td>c Perinatal Post Mortem Request Form completed</td>
</tr>
<tr>
<td>d Information for parents about Post Mortem Examination of babies and children at St George’s given to parents</td>
</tr>
<tr>
<td>7 Perinatal Mortality Information Form</td>
</tr>
<tr>
<td>8 Bounty Mailing Suppression Form</td>
</tr>
<tr>
<td>9 Bereavement Follow-Up Form</td>
</tr>
<tr>
<td>10 Details entered in ward admission book</td>
</tr>
<tr>
<td>11 Referral to Bereavement Office (Patient Affairs) Form</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>CARE OF BABY</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 Has baby been blessed?</td>
</tr>
<tr>
<td>2 Remove all lines, cannulas, etc</td>
</tr>
<tr>
<td>3 Have the parents consented to photographs being taken?</td>
</tr>
<tr>
<td>4 If yes take photographs, locks of hair, hand and footprints</td>
</tr>
<tr>
<td>5 Bath and dress baby</td>
</tr>
<tr>
<td>6 Place two name bands on baby</td>
</tr>
<tr>
<td>7 Attach one Notice of Death to baby’s clothing, wrap baby in a shawl and attach second Notice of Death</td>
</tr>
<tr>
<td>8 Is baby for Post Mortem (if yes record on Notice of Death)</td>
</tr>
<tr>
<td>9 Record if any memento’s sent with baby to the Mortuary (on Hospital Admission to Mortuary Form)</td>
</tr>
<tr>
<td>10 Request porter to transport baby and nurse escort to the Mortuary (ext 2036)</td>
</tr>
</tbody>
</table>
## INFORM THE FOLLOWING

<table>
<thead>
<tr>
<th></th>
<th>Consultant</th>
<th>Chaplain (bleep 5143) or other religious leader</th>
<th>Bereavement Office (ext 2319/2516)</th>
<th>Labour Ward (ext 2663/2399)</th>
<th>Joan Booker Ward (ext 2659/2660)</th>
<th>Health Visitor</th>
<th>Community Midwife (ext 2413)</th>
<th>GP</th>
<th>Liaison Health Visitor/Paed Nurse (ext 2407)</th>
<th>Hospital Social Worker (ext 2407)</th>
<th>Birth Clerk at Goldsworth Park Child Health Clinic (01483-728201 ext 259)</th>
<th>Neonatal Community Team (ext 3674)</th>
<th>Referring Consultant (if appropriate)</th>
<th>Parent Education Co-ordinators (ext 2972) only if multiple birth</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Yes___</td>
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### INFORMATION TO BE GIVEN TO PARENTS

<table>
<thead>
<tr>
<th></th>
<th>Cause of Death Certificate</th>
<th>Directions to Registrar’s Office</th>
<th>If Post Mortem: A guide to PM Examination</th>
<th>Parent Information Following the Death of Your Baby on NICU</th>
<th>NICU Counselling Service Leaflet</th>
<th>Caring &amp; Memories Booklet</th>
<th>Other relevant information leaflets:</th>
<th>Memory box</th>
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</thead>
<tbody>
<tr>
<td>1</td>
<td>Yes___</td>
<td>No___</td>
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The nurse caring for the baby on the Neonatal Unit on the day of baby’s death is responsible for ensuring **EVERYTHING** on this checklist is **COMPLETED** unless she hands over to another nurse who then becomes responsible for completing the remainder.

Name of nurse________________________ Signature____________________________

Care handed over to:__________________ Signature____________________________

---

18
PATHWAY FOR DEATH ON NICU – APPENDIX 2

(See Guidelines for further explanation of each step on identified page number)

Commence Checklist (Appendix 1)

Discuss with parents the options regarding their involvement in the care of their baby (page 4)
They may or may not feel able to be involved

Is further bereavement support required? (page 4)
This may be needed now or later and includes parents and staff

Would parents like their baby blessed? (page 4)
If yes contact the Chaplain

Discuss whether Post Mortem is required (page 5)
Doctor’s responsibility to obtain consent

Discuss funeral options (page 6)
If parents wish a cremation then it is very important to ensure the Medical Certificate (Cremation Form) is completed the same day

Remove all long lines, cannulas, ETT, etc (page 6)
After discussion with Consultant

Give baby to parents to cuddle (page 7)
The timing of this may vary depending on parents’ wishes

Confirm death (page 7)
Ask Doctor to listen to ensure no heartbeat and record in baby’s notes

Create memories booklet (page 7)
This includes photographs, lock of hair, footprints and handprints

Bath baby (page 8)
Parents may or may not wish to help

Dress baby in clean nappy and clothes (page 8)
Parents may wish to choose clothing

Place 2 x name bands on baby (page 8)
1 on wrist and 1 on ankle as per ASPH Trust policy

Give parents as long as they want with their baby (page 8)
They may also want other family members present

When parents are ready to say ‘goodbye’ (page 8)
Ensure they have all the information as per Checklist
↓
Attach 1st copy of Notice of Death to clothing (page 8)
↓
Wrap baby in shawl and attach 2nd copy of Notice of Death to shawl (page 8)
↓
Place baby in moses basket (page 9)
Or you can carry baby in your arms
↓
Ensure all documentation required is completed as per Checklist (page 9)
↓
Request a porter to escort baby and nurse to Mortuary (page 9)
Remember 2 x Notice of Death Forms, Hospital Mortuary Admission Form and Post Mortem Forms (if required)

**DOCUMENTATION**

*PLEASE COMPLETE ALL FORMS USING BOTH PARENTS SURNAMES (IF DIFFERENT)*

The Medical Cause of Death Certificate and Medical Certificate (Cremation Form) will be needed urgently (page 10)
The Medical Cause of Death Certificate must be given directly to the parents in the white envelope. The Notice of Death Certificate and Medical Certificate (Cremation Form) will need to be taken to the Bereavement Office
↓
Complete Mortuary Admission Form, Post Mortem Consent Form and Perinatal Post Mortem Request Form (if required) (page 11)
These must accompany the baby to the Mortuary and a copy in notes
↓
Complete Referral to Bereavement Office (Patient Affairs) Form and Notice of Death Form (page 12)
This must be delivered by hand as soon as possible to the Bereavement Office.
↓
Complete Perinatal Mortality Information Form and Bounty Mailing Suppression Form (page 11)
↓
Complete Form A Notification of Child Death (page 11)
This must be completed and faxed to the coordinator by the following working day
↓
Ensure memory box and completed memories book is given to parents (page 12)
Together with relevant information leaflets.
↓
Ensure all necessary personnel informed (page 13)
As per Checklist
↓
Ensure date, time and cause of death written in notes (page 13)
↓
Discharge baby on PAS and in ward book (page 13)
Leave baby’s notes with instructions to go to Consultant’s secretary (page 13)
She will offer an outpatient appointment for 4-6 weeks for parents

Complete Bereavement Follow Up Form (page 12)
And place in baby’s notes. This will ensure the family receive appropriate follow up.

Staff Support (page 14)
Ensure YOU have support/debrief.

SUMMARY OF PAPERWORK

Paperwork to go with BABY
Notice of Death Form x 2
Hospital Mortuary Deceased Patient Admission Form
If for Post Mortem: Consent to Post Mortem Examination Form – signed
AND Perinatal Post Mortem Request Form – completed
(place a copy of both of these in baby’s notes)

Paperwork to go with PARENTS
Cause of Death Certificate
Directions to Registrar’s Office (if Surrey)
Parent Information Following the Death of Your Baby on NICU
NICU Counselling Service leaflet
Memories and Caring Booklets
Relevant SANDS information leaflets

Paperwork to go to BEREAVEMENT OFFICE
Notice of Death Form
Medical Certificate (Cremation) Form