Bradford Teaching Hospitals NHS
NHS Foundation Trust

Neonatal End of Life Care

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MANAGEMENT OF END OF LIFE CARE IN HOSPITAL

Care of the dying child

It is important to remember that everyone deals with loss in their own way. Parents' wishes should always be considered and where medically possible, must be accommodated. Parents should be able to feel in control and be supported in decision making. All communication with parents should be clear and honest and privacy and dignity must be maintained at all times.

Place of care

Parents and families should be given a choice of place of end of life care. They should be offered end of life care either in the hospital, the hospice or home. It may not always be possible to offer this choice (depending on the clinical condition of the baby / availability of resources) but every effort should be made to respect family's choice about the place of care.

Communication

Families should be offered an approach that is sensitive to their specific needs. Discussions with parents should be conducted by the consultant leading care of the mother or baby (on occasions it may be delegated to a senior trainee), and should take place in a private and quiet environment, away from the clinical area where possible. Consider using Daisy Suite (quiet room) / Primrose Suite (bigger room) for sensitive and difficult communication sessions with the family. When making difficult end of life decisions, it is important to have a multidisciplinary team – including the nurse looking after the baby who has established rapport with the family to be involved in the discussions. An interpreter should be used if English is not first language of the family. Both the baby's parents should be present, and the parents should be offered the chance to involve extended family or friends in the discussion if they wish.

Important considerations-

- Compassionate extubation
- Pain relief / symptom management
- Feeding and nutrition
- Religious aspects / Spiritual support
- Care after death of the baby

End of life care Checklist

Please use this end of life care checklist for all babies – to be printed and used once decision made about reorientation of care to palliation

End of life care checklist 2019.doc

Compassionate Extubation in the hospital - for ventilated babies

If the family choose to continue care in the hospital, it is important to have discussions about the options including extubation at the cotside or using the Daisy / Primrose suite (oxygen and gas supply available) or the parent bedrooms (Lavender / Clover suite). A snowdrop sign to inform all staff and visitors should be situated on the outside of the door to the room and if possible the Ward Clerk should be informed to ensure that all visitors are made aware of this temporary closure. Furthermore, other staff on the unit such as domestics and HCAs, should be informed to help provide privacy and dignity for the family involved. There are air and oxygen points in the Daisy suite to help provide some time on a ventilator or other breathing support. However, some parents may not want to move into the Daisy Suite and may wish to stay in the nursery, in this case screens can

snowdrop (2).pdf

be utilized and the whole nursery can be closed.

The parents should be prepared as to what to expect when babies are extubated for palliative care. It would be important to talk about potential responses from the baby, uncertainties about duration of survival after extubation, nutrition and analgesia following extubation. Parents should be allowed time before they feel ready for the extubation and should be supported by the multidisciplinary team throughout the process. After extubation, parents should be allowed time in the rooms with their baby and will be able to contact the nurse looking after the baby by using the mobile telephone (**07399643097**), without having to leave their rooms. The baby should be assessed regularly for pain and distress and adequate analgesia/ sedation should be provided according to the guidelines. The attending Consultant / Registrar will be able to examine baby and certify death once there are no signs of life.

Pain and symptom management

Addressing distress and ensuring adequate analgesia / sedation is a key aspect of the compassionate extubation process.

All babies receiving palliative care must have consideration given to relief of pain and discomfort. Assess and treat any underlying causes of pain. Assessment of pain in babies is very difficult, but signs may include:

- Persistent crying
- Furrowing of the brow and squeezing shut of eyes
- Being unsettled and agitated
- Tachycardia

Simple measures such as swaddling, breast feeding and use of a dummy should be employed. If there is ongoing evidence of pain, the following drugs should be used in a stepwise fashion

1. Oral sucrose (24%) as per pain protocol
2. Paracetamol (see formulary / BNFC)
3. Opiates by the route best tolerated by the baby: oral (PO), buccal, intravenous (IV) or subcutaneous (SC).

If a baby is already receiving an opiate infusion at the time of entry to the palliative care pathway this should be continued. If starting an opiate at the onset of pain/distress, oral or nasogastric morphine should be used in a baby who can tolerate enteral medications. For parenteral opiates use IV morphine (only if existing IV line).

In situations where intravenous access is unavailable or deemed inappropriate, subcuataneous infusion of opiates / sedatives (midazolam) is a useful anternative. For instructions as to how to insert the subcutaneous needle, please see video (on shared drive neonat-4, U drive, palliative care section)

Subcutaneous infusions can be administered through the usual pumps in hospital.

Dose of morphine

- By mouth or by rectum
    - 25-50 micrograms/kg every 6-8 hours adjusted to response
- By single SC injection or IV injection (over at least 5 minutes)
    - 25 micrograms/kg every 6-8 hours adjusted to response
- By continuous SC or IV infusion:
    - 120 micrograms/kg/24hour adjusted according to response

The opiate dose should be titrated to response. If there is no response to the starting dose, increase doses by increments of 30-50% as needed to ensure that the baby is comfortable. Consider adjuvant analgesics e.g. paracetamol, ibuprofen, if not already using. Morphine infusion rates of 100 microgram/kg/hr or higher may occasionally be required to effectively treat pain. However it is illegal to give any medication with the main intention of hastening death. If intravenous access is not available, buccal midazolam is an alternative and can be used to address acute anxiety associated with dyspnea towards end of life.

Midazolam (for anxiety / agitation /dyspnea)

Buccal route - 25 micrograms / kg

Oral route – 50 micrograms / kg

Iv / s.c – 25 micrograms / kg (repeated hourly if necessary)

For further information about drug doses, please refer to the 2017 edition of the APPM formulary

APPM FORMULARY 2017.pdf

Feeding and nutrition

Intravenous nutrition and hydration can safely be discontinued in any infant on an end of life care pathway after agreement with parents and other professionals. The goal of feeding neonates towards end of life is comfort – not provision of nutrition. Oral nutrition should only be withheld if it is felt that providing it will cause pain or discomfort. The amount of feeds should be determined by their clinical condition. In some situations, it may be appropriate to allow the infant to suckle at the breast (if they are able to do so). If the mother / parents are keen to offer breast milk to the neonate, they should be supported through expression of breast milk. In infants who are expected to die soon, it may be appropriate to stop all enteral feeds.

Other supportive measures

Management of Seizures

Seizures can be distressing and cause anxiety to parents as well as pain and discomfort to the infants. If the seizure medications have been started already, it may be appropriate to continue the medications (route of administration depending on availability). If seizures occur newly during end of life care, ongoing management of seizures involves careful consideration from a comfort point of view. If no intravenous access is available, buccal midazolam (300 micrograms/kg) can be used to control seizures.

Secretions

Gentle suction and occasional use of (glycopyrronium or hyoscine) may be warranted if secretions continue to cause distress in neonates towards end of life. (for dosages refer to APPM formulary)

Electronic and invasive monitoring needs to be discontinued before extubating the baby and intermittent physical assessment for pain or discomfort should be carried out post extubation.

RELIGIOUS CONSIDERATIONS

Trust multi-faith representatives are accessible and can be contacted via the Chaplaincy. (See guidelines on chaplaincy cover).

Alternatively, families own religious representatives can visit the unit to provide spiritual support for the family and religious ceremonies or prayers can be facilitated.

Below is a guide – it is best to ask the family about their customs and beliefs. Sensitivity to these issues will bring comfort and support to those who need it. Do not make assumptions about what a family may or may not require.

ISLAM

- A dying Muslim may wish to sit or lie facing Mecca (South East in Britain). Cots/beds may need to be moved.
- Family members may recite prayers around the bed/cot and may perform all rites and ceremonies.
- It is not always necessary to have religious leader (Imam / Maulana). If there is no family present, any practising Muslim can help.
- Contact the Multi-faith Team.
- After death the body should not be touched by non-Muslims. If health care workers need to touch the body, they should wear gloves. The following steps are usually undertaken by a Muslim, but if the family are willing:

  -Close the eyes.

  -Bandage the lower jaw to the head so the mouth does not gape

  -Flex the elbows, knees and hips before straightening them.

  -Turn the head towards the right shoulder (so the body can be buried with the face towards Mecca).

  -Do not wash the body or cut the nails

-Cover the deceased with a plain sheet, which conceals the whole of the body.

- A Muslim funeral should take place as soon as possible.
- Muslims are always buried, never cremated.
- Post mortems are forbidden, unless ordered by the Coroner, clear explanations are needed.
- The subject of organ donation should not be raised unless initiated by the family.

Live baby who dies

A baby who is born alive and then dies should be given a name, bathed and shrouded; the funeral prayer (Janaaza prayer) is recited prior to burial. Private funeral is required.

Bathing

Facilities are available on the delivery suite for families to undertake this ritual (ghusl). Either male or female family members can perform this ritual; however the mother should not as she will be bleeding. This is because the bath is considered an act of worship. She may observe. The person performing the bath should be in a state of ablution (wudu) and it is preferable for him/her to bathe following the washing of the body. Water used for this ritual must run off the body. A small "ramp" with a baby changing mat and jugs are kept in the equipment room on the delivery suite to facilitate this. When relatives are unable or reluctant to undertake the bathing, they would appreciate this being performed by a member of staff, who should wear gloves. Once the body is wrapped, it must not be disturbed. If families are making private funeral arrangements, the funeral directors will perform bathing.

HINDU DHARMA

- Dying Hindu may wish to be bathed in running water, which signifies being spiritually clean as well as physically.
- Hindu patients may wish to die at home which has religious significance.
- A dying Hindu may receive some comfort from hymns & readings from holy books. - -
- Some may wish to have images, pictures, prayers or beads on or near the bed.
- Some may wish to lie on the floor symbolising closeness to Mother Earth.
- A Hindu priest (pandit) may be called to perform holy rites- the Priest may tie a thread around the neck or wrist of the dying person to bless him/ her.

- Blessed water from the River Ganges may also be sprinkled over the dying person or a sacred Tulsi leaf placed in the mouth.
- Relatives may bring money or clothes for the patient to touch before distribution to the needy.
- The body should be handled by his/ her family members as far as possible.
- The body should not be washed – it is usually carried out by the relatives later- the male body by a male relative and the female body by a female relative.
- If necessary disposable gloves should be worn and the following carried out:

  -Close the eyes and straighten the limbs Jewellery, sacred threads and other religious objects should not be removed.

  -Wrap the body in a plain sheet without religious emblem.
- All adult Hindus are cremated, preferably within 24 hours. Infants and young children may be buried.
- Post mortems are disliked, however prior permission may be obtained. Some Hindus would consider it disrespectful to open up a dead body and some may not consider organ donation.

SIKH DHARAM

- A dying Sikh may receive comfort from reciting hymns from the holy book- if unable to do so a relative or reader from the Sikh Temple may do so instead.
- The family usually wash and dress the body after death and hymns are often recited whilst doing this. In general, non-Sikh may tend the body (inform the family where possible) and the following steps should be taken:

  -Close the eyes, close the mouth

  -The face of the deceased may be displayed on numerous occasions prior to the funeral – a peaceful expression is desired. Therefore, it is appreciated if the face is cleaned, straightened if necessary the eyes or mouth closed.

  -Limbs should be straightened and the body covered in plain white sheet or shroud without religious emblems.
- There are five symbols (the 5K's) which a Sikh may have on his/her body. These should not be removed but be given special regard. A Sikh is cremated with these 5K's:

1. Kesh – uncut hair-should not be cut (includes beard). The hair on the head should be covered
2. Kara – steel wrist band

3. Kirpan – a symbol short sword or dagger
4. Kaccha – short trousers/breeches
5. Kanga – small comb

- Sikhs are always cremated, preferably within 24 hours. The ashes are collected and scattered in a river or sea.
- No religious objection to blood transfusion, organ transplant. Post mortems are to be avoided where possible.

JUDAISM

- A dying Jew may wish to hear or recite a special prayer, the Shema, or special psalm, particularly Psalm 23 (the Lord is my Shepherd) and a special prayer. They may appreciate being able to hold the page on which it is written.
- Traditionally, the body should be left for about eight minutes while a feather is placed over the mouth and the nostrils and watched for signs of breathing.
- A non-Jew should not touch the body. If there are no signs of life the son or nearest relative does the following:

  -The eyes and mouth should be gently closed

  -The arms are extended down the sides of the body

  -The lower jaw is bound
- The family may ask that a rabbi is contacted or the local synagogue so that the "chevra Kaddisha" the holy assembly might carry out the last attentions to the dead. Preferably they or the family, or, if that is not possible, staff with gloves on should remove any tubes etc. Traditional prayers are said as this happens.
- The body should be covered and left untouched – traditionally the body is placed on the floor with the feet towards the door, covered with a plain sheet and a lighted candle is placed just above the head.
- The body should be left on its own-The body should be handled as little as possible by others and burial should take place as soon as possible, preferably within 24 hours (except if on Sabbath)-The Sabbath starts before nightfall on Friday and ends with the first sighting of three stars on Saturday evening, hence it begins and ends at different times over the year.

- Orthodox Jews are always buried but those of a more liberal Persuasion may choose cremation.
- There are usually separate Jewish burial grounds.
- Post mortems are not permitted by Jewish law except as required by the law of the land. A rabbi should first be consulted.
- Orthodox Jews may object to organ transplants.

CHRISTIANITY

- A dying person may wish for a priest or minister to come and administer one or more sacraments. These are:

  -Baptism – a person may wish to be baptised or parents may wish for a child or baby to be baptised. A priest /minister should be called but in an emergency a Christian member of staff may baptise, placing water on the baby's / person's head saying "I baptise you in the name of the Father and of the Son and of the Holy Spirit Amen" If a child dies unbaptised, the Chaplain may offer a blessing and naming ceremony after death, or baptism in some cases.

  -Confession/ the Sacrament of Reconciliation – privacy to share one's deepest concerns is important for a dying person.

  -Holy Communion /The Viaticum (provision for the journey) is received as a means of strength and grace to assist the dying person. Sometimes family and friends may want to join in the service.

  -The Sacrament of the Sick.

  -Anointing and Laying on of Hands (Last Rites) the family may wish to be present.
- Prayers may be said at the bedside and Bible passages read, a family may request a Chaplain, minister or priest to do this.
- A family may wish to view the body especially if they were not present at the time of death either in the hospital ward or in the mortuary.
- There are no religious objections to post mortems or organ donation
- Either burial or cremation may be acceptable

Note: The differing denominations (Anglican/Church of England; Roman Catholics and Free or Non-Conformist Church) place differing emphases on the above. In the Roman Catholic Church the Sacraments are extremely important to the dying and a priest should be called at the earliest

opportunity, to the critically ill, so that the sacraments of reconciliation (confession), anointing and Holy Communion can be administered properly. Other Christians may vary in their desire for the sacraments, formal and informal prayer and should be asked what their specific needs are (BHNHST 2006).

In The Event Of an Emergency Baptism:

1. Ask what denomination of parents.
2. Contact Chaplainancy on #5819 and ask for Chaplain to attend. Remember to state denomination e.g. Roman Catholic, C of E and Baptist etc.
3. However, in the case of necessity, any person can baptise provided that he/she has the intention of doing what the Church does and provided that he/she pours water on the baby's head while saying:

Name … I baptise you in the name of the Father, and of the Son and of the Holy Spirit.
(If the baby/foetus is doubtfully alive, according to Roman Catholic practice, add the words. "If you are alive"…. "I baptise you in the name of …."

Then Contact the Chaplaincy Office on 5819 and pass on the following details:

- Child's name
- Parents name(s)
- Date of birth
- Name of person who baptised
- Names of any witnesses

Please be aware that the Church of England Chaplains and the Free Church Chaplains may baptise a child that has died, if requested. A naming and blessing ceremony may also be offered instead of baptism.

Note: wherever possible the Chaplains will always want to offer pastoral/bereavement support to families so please always contact them.

Guidelines for Emergency Christian Baptism

(Roman Catholic Families)

In the event of a danger of death situation, where the Chaplain may be unable to be present, it is possible for anyone to baptise by simply pouring water on the baby's forehead while saying the words:

NAME …. I BAPTISE YOU IN THE NAME OF THE FATHER …….. AND OF THE SON ……. AND OF THE HOLY SPIRIT

If there is a doubt whether the baby is alive or not, add the words, "If you are alive".

Note: For the baptism to be valid the person pouring the water has also to be the one who recites the words. Holy Water is not essential but the water has to be real and natural.

In the event of an emergency any member of the healthcare team can baptise, whether they are a believer or not. If they are of a different religious belief they can still baptise, providing they feel comfortable and use the above formula and do so with the intention of doing it according to the mind of the church.
What to do after the baptism: Record the child's name and the parents' names, the date of birth, the name of the person who baptised and the name of a witness who was present and forward it to the Chaplaincy Office at St. Luke's Hospital.
It may be important to remind parents that having their baby baptised at this point does not preclude the possibility of partaking meaningfully in the baptismal ceremonies at a Church later.

In some circumstances the following may be helpful:

1. If only the baby's head can be reached and if there is immediate danger of death the child may be baptised upon the head. The baptism is not repeated conditionally if the child lives.
2. If only a limb is presented the infant may be baptised upon the limb (e.g. foot) but the child must be baptised conditionally if it is born alive.
3. If the baby is delivered of a mother after her death and shows signs of life it shall be baptised absolutely and conditionally if life is doubtful.

4. Regardless of how the pregnancy loss occurred baptism is to be conferred as long as the baby is alive. If the baby is clearly dead, baptism cannot be conferred. In cases of doubt as to whether the baby is alive or not, the baby should be baptised conditionally.

That is "If you are alive" using the words "Name …. I baptise you, in the name of the Father (pour water) …. and of the Son (pour water) …. And of the Holy Spirit (pour water).

Please refer to the guidelines on Chaplaincy availability for neonatal unit 
Chaplaincy Cover for Neonatal unit.docx

DOCUMENTATION/ PAPERWORK

Burial of your baby form

Complete the top section of this form, mothers name and date of birth must be included, and then other sections as applicable. If a hospital funeral is required this form MUST be placed in the provided envelope and hand delivered, by a porter, to the main desk. If it is a private funeral, it must be signed by either parent and the form can be filed in the baby's notes.

Notification of neonatal death

Forward to Julie Key (Bereavement Support Midwife). Please complete the form in full and if possible post in letter box no 22 (outside porters room) instead of internal post.

Release of body directly from ward form

Complete this form if the baby is to be released from the ward. Ensure this form is signed by the person taking the baby from the ward. This can be either a funeral director (with identification) or family representative. This form is then filed in the notes.

Mortuary transfer form

This form should be completed and given to the nurse or porter who will take this with the baby, when going to the mortuary.

Mortuary cards

Two copies are needed. One should be attached to the baby's clothing and one attached to the outside of the white mortuary bag. If a baby is released straight from the ward a mortuary card should be completed and sent to the mortuary. A message should be left on the mortuary answer machine informing them about releasing a body from the ward. The baby **must** have two name bands on which include **date of birth** and **date of death**.

Death Certificate

Please discuss the cause of death with the Consultant and this need to be agreed upon and documented in the notes. If the cause of death is unclear and the coroner needs to be involved, do not issue a death certificate. In some situations where a post-mortem is requested, it may be possible to fill in a death certificate. This needs to be discussed with the consultant involved. ***Please note there are two different certificates depending on either the infant dies before or after 28 days of age***. The death certificates are kept in a box file in Room 1. The sections about post mortem and whether the child has been seen after death need to be completed.

When filling in dates at the top of the main form remember you have to spell the date out i.e. 'third or 3rd' day of 'March' … '2020'. On the other sections left/right of the main form you can use 03/03/2020.

When you sign at the bottom of the form your name make sure you add your GMC number and qualifications, and for contact details use the ward/hospital address (not your home one). If you have a contact number for ward/office you can add this for contact details. For deaths in hospital write below in the section required the child's main consultant.

https://www.gov.uk/government/publications/notification-of-deaths-regulations-2019-guidance

Request for Post Mortem (if applicable)

Guidance for obtaining consent and the forms that need filling are available in the documents folder (in Daisy suite). There is an information leaflet for parents and a consent form that needs to be completed by the senior clinician. The post-mortems are carried out in Sheffield and there is a form that needs to be filled in after obtaining consent.

This form has three copies and the family is usually asked for consent. However, the medical team have the final decision. The form should be completed by the medical team.

White Copy Send with baby

Green Copy Give to Parents

Blue Copy File in notes

Please send baby to Mortuary as normal and they will make appropriate arrangements.

Yellow cremation forms (if applicable)

Discuss funeral options with the family and if they want to cremate the baby, a cremation form should be completed. There are two parts of the cremation form, the person certifying death should complete the first part. On occasions, families may not make a decision immediately and the person not certifying death may have to fill in the cremation form. In such situations, the person had to have examined the baby after death to be able to fill in the cremation form. These should be completed for any baby who is to be cremated either in a private cremation or hospital cremation. The doctor completing the death certificate should also complete this. This needs to stay with the baby.

Evolve notification

Any death in the neonatal unit / or in hospital needs to be notified through the Evolve system. This could be done by the doctor or nurse looking after the infant. You will need a trust IT login and password to access this system.

Further information is available on 
Evolve DDS Death Notification Crib Shee

Notification of Child Death Form

To be completed in full and sent to Louise Clarkson (SUDI/COPD manager) MI, Maternity. Louise Clarkson (CDOP manager) will then inform **Child Health** using this form.

PMRT

Parents need to be aware of the Perinatal Mortality Review Process and the fact that they are welcome to contribute to it. This will be discussed with the parents by the Consultant Neonatologist around or after the death of the baby (included in end of life checklist). Parents should be given the following leaflet with the bereavement pack.

PMRT paragraph for booklet.doc

SUPPORTING THE FAMILY AFTER THE DEATH OF THEIR BABY

Verification of Death

A member of the medical team will confirm the baby's death.

Creating Memories

Creating memories is a very important part of the grieving process. We should offer parents a memory box. We have the 4Louis boxes and the Islamic faith boxes. These can be added to with things such as:

- Baby's hand and foot prints
- A lock of hair
- Baby's name bands
- Photographs of parents and baby/ siblings/extended family
- CPAP hats, BP cuffs, saturation posys and cannula splints

It is important to understand the family's wishes about specific memory items as they vary among families and are based on cultural and religious practices. Consider using the memory boxes (4Louis boxes / Islam faith boxes) – located in the x-ray store room. The family may also want to send a toy or religious object to the mortuary with the baby. Photographs of baby, use of family's camera, unit camera and/or "Remember my baby charity" (Laura Sunderland – 07905179128, www.remembermybaby.org.uk) (The appropriate consent form needs to be signed

RMB_09_CONSENT_FORM_20160406.pdf

RMB_05_Introductory_letter_08042015.p

RMB_Minimum gestation guidelines_.

Verbal permission must be sought before obtaining hand/footprints or locks of hair

We encourage parents to take photos of their baby and if they would like us to then we can take photos for them to keep on a memory card. If the family do not wish to have photos taken then they could be done when family have left the ward and kept in the baby's hospital file in a memory card,

and should parents wish to have them in the future they will be available for them. Any disposable items that their baby has used such as ID bands, CPAP masks and BP cuffs should also be kept.

Bathing/ washing baby

If parents would like to bath/wash their baby we can provide them with everything they need to do this. Baby wash, wash cloths, powder and clothing is kept in the X-ray room. One full outfit can be provided if parents do not have their own clothes eg. Vest, baby grow, hat and these are for them to keep. We also have some knitted blankets in different sizes for families to keep. Bathing can take place where parents feel most comfortable or where is most appropriate at the time. Options include the Daisy or Primrose Suite, Parents Bedroom, Birth Centre pool if available or bedrooms on M2.

Support from family/friends

At this time parents may want to have their friends and family around them, visiting will be unrestricted during this time and we should ensure they have space and privacy to grieve.

NOTE- Parents should be offered the use of the unit mobile (07399643097) to ensure that they are given privacy yet feel they can contact us at any time without having to leave their baby.

Care of babies after death

Once the family have left, the baby could be placed in the cold cot in the Snowdrop Room or in the fridge in Snowdrop until transfer to the mortuary. The cold cot is available in the store room and this will enable us to keep the baby in the bedrooms with or without their parents. However, we need to be cautious if we are looking after a big baby or if the room is too warm. No baby should be left in the cold cot by themselves and if they are in the bedroom, they need frequent monitoring. Further instructions for usage of cold cot are available here –

Flexmort-Cuddle-Cot
-User-Guide-Dec2012

The baby should be washed if the family did not wish to do so and if this does not contradict religious considerations. If it is necessary to wash the baby for medical reasons then this should be done wearing gloves.

Transferring Baby

If the baby is to go to the mortuary, some parents may wish to take their baby to the mortuary with you, others may prefer to leave baby in the hospital and for us to do the transfer. This should be discussed with the parents. Please contact the mortuary so that they are aware of the pram transfer. They usually do not want us to use the office side entrance or the main door but the entrance next to the main door. Please clarify beforehand. The porters will need to be contacted for the key if out of hours. The pram should be used to transfer the baby in a dignified manner. Parents cannot enter the mortuary but may wait in the foyer.

What is needed for mortuary transfer?

- Baby can be dressed
- Baby will need a clean nappy, ensuring no leakages. All IV lines to be removed.
- To have two ID bands with DOB and DOD on
- Wrap in white sheet with mortuary card on, then placed in body bag with mortuary card on

Taking baby home

Parents may wish to take their baby home. Providing there is no post mortem, this can usually be facilitated. The 'Release of Baby from the Ward' form must be completed and filed in the medical notes. The mortuary should then be informed by phone and sent a copy of the completed mortuary card, via the porters.

Leaflets

Please ensure all relevant information are given to parents. SANDS leaflets on 'The Loss of Your Grandchild', 'Mainly for Fathers', 'About the Other Children', 'For Friends and Family' and 'Next Pregnancy' can be found in Daisy Suite drawers with the Bereavement packs. Bereavement books for siblings will also be kept here. There is also a SANDS app which some families wil find useful.

Funeral Arrangements

Following a neonatal death, a funeral can be arranged by the trust or private arrangements can be made

Hospital Burials

- The baby will be buried in one of three communal graves reserved for babies at Scholemoor, Nab Wood or Scholemoor Muslim cemetery
- An individual coffin and funeral service are provided, free of charge
- The grave is a large vaulted area each holding approximately 100 coffins. The family should be made aware that there are other babies in the grave, yet at the funeral they are not visible.

Hospital Cremation

- Parents choosing a cremation should be made aware that is highly unlikely that there will be any ashes due to the size of the baby. An individual coffin and funeral service are provided. Cremation may take place at either Scholemoor or Nab Wood Cemetery.
- An individual coffin and funeral service are provided
- A memorial plaque can be ordered via the Cremation Office, if desired
- Parents will be contacted by the Trust to be informed about when the funeral is to take place and arrangements can be made for their own religious support.
- Parents can also make their own funeral arrangements, however parents will be responsible for any cost incurred.
- If the family choose to have their baby cremated, a cremation form needs to be done.

Out of area Babies- ensure contact is made with babies 'home' hospital to arrange funeral/cremation and give necessary details. See out of area unit details sheet.

Out of area contact numbers for hospital funerals

Airedale	-	Neonatal unit	01535 652511
Dewsbury	-	Bereavement office	01924 816096
Calderdale	-	General office	01422 222088
		Neonatal Unit	01422 224421
Harrogate	-	Chaplaincy department	01423553188
		General office	01423 553045

	Neonatal unit	01423 553188
Leicester Royal	Neonatal Unit	0300 3031573
	Mortuary	01162 585596
Pinderfields	Bereavement office	01924 541016
Rotherham	Neonatal unit	01709 304488
	Chaplaincy department	01709 424098/425194

Contact the above numbers for advice when a family require a hospital funeral.

It is **our responsibility** to contact the home hospital and pass on the details of the family so they can arrange the funeral with the family. Make sure you have all the relevant information including contact details for the family. Some hospitals may not arrange free funerals so please check first before informing parents.

Registering death of a baby

When a Medical Certificate of Cause of Death is issued, you are required to make an appointment to register the death. An appointment can be made by either contacting the site registrar or the local registry office. It is generally expected that registration takes place within 5 working days. If the Coroner decides a post mortem is required he / she will issue all the relevant paperwork after the post mortem has taken place and advise you of how to progress.

Local Register Office

Bradford and Keighley Register Office

City Hall	Site Registrar
Centenary Square	Level 1 (Ground)
Bradford	BRI
BD1 1HY	Tel: 01274 364477
Tel: 01274 432151	

Registering requires an informant, this is normally a parent. If you are married, either parent can go. If you are unmarried and would like both parents' names on the certificate, then this can done, providing both parents are present to register baby. You can only register a forename for your child at this time, it cannot be adjusted later.

A neonatal death must be registered within 5 working days. You can register the birth and death at the same time. The medical team will give you a neonatal death certificate; this may not be able to be given to you immediately. We can contact you when this is ready for collection.
At the time of registration you will receive a Certificate of Burial/Cremation, a short copy of the Birth Certificate and a copy of the Death Certificate.

A funeral cannot take place until the Certificate of Burial/Cremation is issued.

If babies are born elsewhere and die in our NNU, it is possible to register them here but there might be delays in processing the paperwork and it is advisable for them to register in the place where they were born. If there is any problem with registration, the hospices will be able to provide support and advice.

Registrars are available:

Hospital: **Monday- Friday** between 10:30 -14:45
By appointment only

Register Office: **Monday- Saturday** between 09:00 -16:00
By appointment only
On call Sundays and public holidays
Between 09:00-11:00

RESOURCES

X-ray Room Cupboards

Left cupboard

- Books
- Cold cot / Moses Basket / Gowns

Middle cupboard

- 4Louis/Islamic faith Bereavement Boxes
- Assortment of blankets
- Bags for babies belongings

Right cupboard

- Books for siblings /Baby wash items
- Toiletries for parents / Spare clothing for mums / Towels

Daisy Suite Drawers

Large Drawers

Top of bureau	Tissues / Tea Set
Middle Shelf	Book of Rememberance
Bottom shelf	Prayer mats and 1 Quran
Top drawer	Baptism and Christening items
Second drawer	Information leaflets – hospice / SANDS / others
Third drawer	Bereavement packs, spare paperwork, PM, and snowdrop/ butterfly signs

Small Drawers

Drawer 1 and 2	Islamic books / prayer mat
Drawer 3	Nappies, cotton wool, wash bowls, name bands, plasters
Drawer 4	Blank cards, gloves, story books

ORGAN DONATION

Organ donation is a sensitive topic to approach with families around end of life and should be handled appropriately. Some families will not be interested in donating their babies organs and this needs to be respected. For further information on organ donation you can go to www.organdonation.nhs.uk.

Although parents need time to grieve and be alone with their baby it is important they are made aware of this option before donation is too late. The best time for donation is within 24 hours after someone has died. However, sometimes it is possible to donate up to 48 hours after death. The topic of organ donation may be best approached by the consultant or senior nurse and only when parents are ready and comfortable to discuss it. A leaflet on organ donation should be given to all families that way families can read it, if and when they feel comfortable to do so.

Donated heart valves can be stored for up to 10 years. All other donated tissues, apart from eyes, can be stored for up to five years. Donated eyes can be stored for up to one year, but if suitable for transplantation they are often transplanted within a month.

To speak to the Organ donation coordinator, please contact them through the switchboard. (24 /7)

Online:www.organdonation.nhs.uk

Tel: 0300 123 23 23


Neonatal organ donation (2).pdf


INF1299_Organ_Donation_and_Babies_wi

End of Life care at Home or Hospice

We are able to offer choices to families about ongoing place of end of life care. Some families may wish to spend time with their child either at a hospice or at home (being supported by children's community palliative care team or from a hospice). Neonates born and cared for at BHTFT Neonatal unit have access to two hospices within the region – Forget Me not Hospice (Huddersfield) and Martin House Hospice (Wetherby). The information about hospices is available in the resources section and the families are offered a choice between the hospices and home for continuing care. Many families may prefer to care for their infants within the hospital and use one of our family rooms / bedrooms and be supported by the neonatal team.

Care at Hospice

For families who would make a choice of either hospice, the care team for the hospice need to be contacted prior to offering of transfer to ensure that they can look after the infant at a given time. Their contact details are as below

Forget me Not Hospice Care Team	01484 411042
Martin House Hospice	01937845045 / 01937844836

If the infant is receiving intensive care and the families would prefer a compassionate extubation in the hospice, this needs to be discussed with the respective hospice and Embrace team to enable transfer of babies to the hospice. If there is time, it would be important to facilitate a consultation with the hospice team and the parents. The parents should also be offered a visit to the hospice if appropriate / time permits.

Once a decision is made to transfer a baby to the hospice for ongoing care, the following need to be completed

1. A complete discharge summary and a clinical handover to the hospice care team
2. Advance Care plan with anticipated management plan for sudden deterioration – analgesia, level and extent of resuscitation - For this purpose, the latest version of the CYPACP – RESPECT form should be used. This is a comprehensive document that identifies their needs and gives guidance on their clinical management. This needs to be filled in by the consultant neonatologist in close liaison with the palliative care team – community / hospice.


CYPACP - Respect form v4.pdf


CYPACP - Respect form (electronic v 4).

3. On situations where an advance care plan is not deemed necessary but if limitation of treatment agreement (LOTA) needs to be in place – the last 2 pages of the RESPECT document allows the clinical team to make specific recommendations about managing resuscitation. This needs to be filled in and filed in patient notes and copies shared with relevant professionals.
4. Once the LOTA has been agreed on, please change the Resuscitation Status on EPR to LOTA (rather than full CPR) and the LOTA document can be uploaded as a clinical note. For further instructions see


Changing resuscitation status o

5. Medications as appropriate. If the hospice requests us to send the babies over with oral morphine and midazolam 

These need to be prescribed on the CD prescriptions (kept in CD cupboards in room 1).
6. If babies are transferred to hospice / home with subcutaneous infusions of sedation / analgesia, liaise with the children's community palliative care team to procure a Mckinley infusion pump and with the Neonatal pharmacist about infusion doses / composition.
7. Coordinate transport with Embrace / Hospice (depending on the condition of the infant)

If the babies are not on intensive care and are not on breathing support, the hospice might be able to facilitate transfer and it is important that this is discussed with the hospice. On occasions, families might benefit from spending few days at the hospice prior to going home for end of life care (STEP DOWN). In these situations, it is important to make sure that the above mentioned steps are completed.

Care at Home

For families who would prefer to care for their infants at home for end of life, the process needs to be facilitated with close input from either of the hospices (parental choice) and the children's community palliative care team (Catherine Brown (5296). If the infant is expected to live for days / weeks it is important that a multidisciplinary discharge planning meeting is arranged between the professionals (community palliative care team, continuing care team, neonatal outreach, HV, GP, Hospice care team) and clear plans made regarding care at home – feeds, resuscitation in terms of acute deterioration, choice of place of care in the event of illness, care if the infant dies at home, death certification and post-mortem investigations (if appropriate). These needs to be clearly addressed in the care plan and a copy should be made available to the parents and shared with all professionals responsible for the infant's care. Infants who are discharged home on an end of life care plan may need direct access to CDA and the care plan / LOTA needs to be shared with them.

Further guidance about LOTA may be accessed through the following link


SOP for initiation implementation and d

Bereavement support / follow up

All families are offered a follow up appointment (usually after 8 weeks) following the death of an infant. The appointments will be arranged by the secretaries and it is useful to include the nurse who has been involved with the family in the last few days. The appointment could be arranged at home, or in clinic if the family do not want to come back to the unit. If either of the hospice team is involved, it would be good practice to have their input.

Please use the bereavement follow up pack to give parents appropriate information.

Families can access either of the hospices for ongoing emotional support / counselling / sibling support. This can be arranged through the care team even if families have not had any input from the hospices for end of life care. The Community Palliative Care Team will also be able to provide sibling support and emotional support, especially if they have been involved in the infant's care at home.

External Support

- BLISS, SANDS and Julie Keys (Bereavement midwife) contact numbers are included in the bereavement pack
- Hospice referral – Families can be referred to the hospices for emotional support following loss. A choice is offered to the families regarding the hospice (Martin House /Forget me Not) and even if the families are undecided, the leaflets are given to the families, in case they would need support later.
- Chaplaincy
- Multidisciplinary follow up – A consultant led follow up appointment is arranged with the family and it is preferable to have the nurse who has led on the baby's end of life care to be available during this appointment. A choice is often offered about the place of the appointment (according to the family's and clinician's convenience). It is important to involve the hospice team or the children's community team if they were involved in the infant's care. The Trust 'bereavement carer's survey' needs to be distributed to families at this appointment for ongoing feedback.
- Child Bereavement UK (CBUK) are offering support through, phone, email, text, live chat and virtual calls. Families can be referred to Nicola Clarke at **nicola.clarke@childbereavementuk.org**.uk. She is available 9-5 Monday to Friday through email (preferable) or phone 07825393360 . At other times, the CBUK National help line (0800 02 888 40) is available 24X 7 for families to contact.

The Trust hosts 'Shared memories' service twice a year (one in summer / one around Christmas) and the parents are invited to this ceremony. The invite is coordinated by Suzi and Louise Clarkson (CDOP) team and for further details please contact Joe Fielder (Chaplain). There is also a 'Book of Remembrance' – that is kept in Daisy suite that the parents are welcome to contribute to. Parents are invited to contribute something in writing in the memory of their infant along with pictures and this needs to be sent to Suzi). We will arrange a calligraphist to write in the book at regular intervals.

Some useful resources

When your baby dies

https://www.childbereavementuk.org/Handlers/Download.ashx?IDMF=2dd77275-498c-4142-b63a-60b4e940f003 - When your baby dies

https://www.childbereavementuk.org/Handlers/Download.ashx?IDMF=93113a54-1833-41b6-bc0e-9af6c8811838 - partners may grieve differently

https://www.childbereavementuk.org/Handlers/Download.ashx?IDMF=204d39ee-627a-42a8-9179-9adf2a746b83 saying goodbye to your baby or child

https://www.childbereavementuk.org/Handlers/Download.ashx?IDMF=75780a28-43e1-49c4-abb3-6af086307d65 – explaining, stillbirth, miscarriage or death of a newborn to a young child

https://www.childbereavementuk.org/Handlers/Download.ashx?IDMF=8781a00a-6ed6-45a3-81e4-00ce3575a7f5 - looking after yourself

Bradford Royal Infirmary
Neonatal Unit
Duckworth Lane
Bradford
BD9 6RJ
01274 364522

Dear

I am writing to you on behalf of all the staff on the Bradford Neonatal Unit. Firstly I would like to begin by offering our condolences to yourselves and your family at this difficult time and remind you that we are still thinking about you.

During discussions surrounding the recent loss of _____ it is possible that we may have mentioned to you that we keep a Book of Remembrance on the Unit. The aim of this book is to create a lasting memory of all babies who do not make it home with parents. In this book we will

record the name of your baby, date of birth and the date that baby passed away. In addition to this we can add in a poem or some special words from parents. We can also include a picture if you wish to provide one.

Whilst many families do like to leave a message this is not a requirement and if you chose not to reply to this letter we will respect that decision. If on the other hand you do wish us to add some words or a poem please either add them clearly in the space below or on an attached sheet.

recommended that you call the unit ahead of any visit so that we can ensure that we can accommodate you appropriately.

As we are aware photographs of your baby will be very valuable to you, if you choose to provide one we would recommend delivering this by hand or by recorded post to ensure safe arrival.

Once again we are very sorry for your loss and hope that this letter hasn't caused you any further distress.

Yours Sincerely
Suzi Minchella (Senior Sister Neonatal Unit)

Baby's name	Mother and father's name	Address	Contact number
Hospital number	Gestation	Date of birth	Date of death

Checklist	**Tick**	**Signature**	**Date**
Photos taken of baby			
Photos given to parents			
Memory card given			
Discuss 'Remember my Baby'			
Memory box (4louis/Islamic) offered to parents			
Including Cot card			
Name bands			
Hand/foot prints			
Lock of hair			
Red book			
Chaplain or parents own religious advisor notified (if desired by parents)			
Religious ceremony offered/performed			
Consultant Obstetrician informed			
If out of area family- contact 'home'			

Checklist	**Tick**	**Signature**	**Date**
hospital (see out of area contact sheet)			
Bereavement Support Midwife (Julie Key) By phone 4911 By letter (post in letter box 22 outside porters)			
Notification of Child Death form (complete in full and send to Louise Clarkson on M1)			
Outreach Team informed and Evolve letter given (they will update System One and inform HV)			
GP informed By phone			
By Evolve letter			
Evolve notification completed (using Trust log in)			
Child Health to be informed via email by louise.clarkson@bthft.nhs.uk with details of name, DOB, DOD/time and NHS number			
Hearing screen cancelled (2452)			
Outstanding outpatient appointment cancelled			
Inform Cardiologist/Geneticist if applicable			
Consent for post mortem requested			
Consent given/refused			
If refused, other investigations requested			
Consent given/refused			
Post-mortem form completed and			

Checklist	**Tick**	**Signature**	**Date**
signed by both parents			
Mortuary informed (4165)			
Mortuary transfer letter completed			
Two mortuary cards completed			
Death certificate completed and explained			
Certificate with envelope given to parents			
Information given to parents regarding registering death.			
Cremation form completed, if appropriate			
Information of funeral arrangements discussed. Ensure correct parental contact details are documented			
'Burial of your baby' form completed and taken by hand to Bereavement Services, Ground Floor, BRI (must be signed by parents if private funeral)			
Parents informed about Book of Remembrance			
Parents informed of twice yearly memorial service. Invitations will be sent to home address			
Parents informed of a 6/52 Outpatients appointment with their named Consultant			
Parents given appropriate advice booklets/SANDS app details			
Contact number for Unit given			

Checklist	Tick	Signature	Date
Bereavement support contact number given: Julie Key (Bereavement Support Midwife) - 364911			

References / Related documents

1. APPM master formulary 2017 – can be accessed at http://www.appm.org.uk/resources/APPM+Master+Formulary+2017+-+4th+edition.pdf
2. End of life care for infants, children and young people with life-limiting conditions: planning and management – can be accessed at https://www.nice.org.uk/guidance/ng61

3. The Royal College of Paediatrics and Child Health (RCPCH) document 'Withholding or withdrawing life sustaining treatment in children: A framework for practice': http://www.rcpch.ac.uk/what-we-do/rcpch-publications/publications-list-title/publications-list-title
4. The General Medical Council (GMC) booklet 'Treatment and care towards the end of life: good practice in decision making': http://www.gmc-uk.org/guidance/ethical_guidance/end_of_life_contents.asp
5. Guideline for Babies under the care of Neonatal Services Requiring Palliative or End-of-Life Care – Leeds Teaching Hospitals NHS Trust – Clinical guideline – Dr. Sharon English