

DEATH AND SERIOUSLY ILL BABIES

Consultant must be involved immediately in the care of a seriously ill baby

GUIDANCE

Preparation

- Most neonatal deaths are anticipated and often occur following withdrawal of intensive care. The neonatal staff in conjunction with the parents should plan the care of the baby around death
- If baby's condition deteriorates seriously, discuss immediately with **on-call consultant**.
- **On-call consultant** will assess the situation with nursing and medical team, ensuring thorough documentation

Discussion with parents

- If death is inevitable, consultant will discuss with parents
- ensure baby's nurse is present and document discussion
- Use Royal College of Paediatrics and Child Health **Making decisions to limit treatment in life-limiting and life-threatening conditions in children: a framework for practice** as appropriate – see www.rcpch.ac.uk/what-we-do/ethics/ethics
- If appropriate and local policy, review baby for organ donation
- discuss with organ donation team before approaching parents
- further guidance available via www.odt.nhs.uk/odt-structures-and-standards/clinical-leadership/national-organ-donation-committee-paediatric-and-neonatal-sub-group/
- If organ donation not appropriate or considered, then proceed to ask parents if they wish a religious or spiritual person to be involved
- **Complete the Midlands Newborn Network Integrated Comfort Care Pathway (ICCP). This document:**
 - acts as a record of events and a guide for palliative care
 - contains useful links for further information
 - If transfer home or to a hospice, complete Advanced Care Pathway West Midlands, as dictated by local team/hospice

Second opinion

- If there is disagreement amongst the multidisciplinary team or between the team and the parents, consultant to seek second opinion from a colleague

Further support

- If parents do not accept second clinical assessment:
- discuss with medical director or deputy
- discuss with parents the option of a further opinion from **consultant neonatologist** from another unit in neonatal network
- Consultant may wish to seek advice from Trust's legal advisers via medico-legal department or on-call manager
- Timescale for events in individual babies may vary from <24 hr to >1–2 weeks

Good documentation is essential

Saying goodbye

- Parents may request a blessing or naming ceremony by a religious representative
- Ensure all family members are allowed time and privacy with baby
- Consider an appropriate place of care for baby, including transfer to a hospice if available/appropriate and parents desire this
- Ensure parents have had opportunity to take photographs of their baby
- if local transport facility unavailable, contact regional transport team to facilitate this

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- Provide a keep-sake box that can include photos, hand and foot prints, lock of hair, cot card, etc.
- If parental ethnicity and religious beliefs allow, offer parents opportunity to wash, dress and prepare baby
- A small toy or other memento may accompany baby to mortuary

DEATH

- When a baby dies there are formalities to be completed. These should be handled as sensitively as possible to minimise emotional trauma to parents, whose wishes should be respected and who should be guided carefully through the necessary procedures
- Following notification of baby's death from attending nurse, a doctor or ANNP should confirm the death and make a suitable entry in the case notes with date and time of confirmation of death
- If the death was sudden and unexpected (e.g. resuscitation failure in delivery suite or in the A&E soon after arrival):
 - if no radiological confirmation of position of endotracheal tube (ETT), another practitioner must verify position on direct laryngoscopy before removal, and the depth of insertion (from lips or nostril) should be recorded. A post-mortem X-ray is not necessary for such confirmation
 - similarly, leave all central vascular catheters and drains *in situ* after cutting short and covered with dressing

Ensure baby's correct registered name appears on all documentation

Formal arrangements

- Neonatal staff will offer advice about registration and funeral arrangements with back-up support from hospital general office/bereavement office
- Involve bereavement midwife early if available
- In some areas, all deaths must be discussed with Coroner's officer. Check the requirements of your local Coroner before issuing death certificate and requesting post-mortem consent
- if you are unable to issue death certificate, a senior clinician must report the death to the Coroner for a Coroner's post-mortem
- If death certificate can be issued:
 - parents make an appointment with Registrar of births and deaths to deliver death certificate, unless Coroner's officer recommends otherwise
- Registrar of births and deaths will issue certificate of authority for burial or cremation, which should be given to:
 - hospital general office, if hospital is burying baby
 - funeral director handling burial, if parents are making their own arrangements

Post-mortem

- Request a post-mortem in all babies not requiring investigation by the coroner. It is parents' right to have this choice
 - give parents an information leaflet to assist their choice
 - if case required Coroner investigation, Coroner determines need for post-mortem and parents cannot choose
- The post-mortem request must come from a middle grade doctor and a witness must sign the fully completed consent form
 - send original form to mortuary with baby, place copies in baby's hospital notes together with copy of death certificate
 - death summary must be completed by middle grade doctor within ≤ 24 hr of death
 - copy of death summary must be sent to mortuary to accompany baby having a post-mortem

Baby transfer

- Special arrangements will be made to transport baby to mortuary according to **local hospital policy**, allow parents to accompany baby if they wish
- some may prefer to see their baby on the neonatal unit if possible or chapel of rest
- Parents may take baby’s body directly from the neonatal unit, once appropriate documentation has been completed (see SANDS website). Where babies are taken will depend upon religious belief of parents or designated funeral director. In all cases strict adherence of **local hospital policy** must apply

Parent support

- Offer bereavement support information (e.g. SANDS, Child bereavement UK, ACT) or counsellor
- Consultant will offer bereavement counselling at 6–8 weeks, or following final post-mortem result
- Arrange an appointment with trained bereavement nurse/midwife specialist if available

Communication

- Inform named obstetrician and neonatology consultants at referring hospital (if appropriate), GP, health visitor, and community midwife that death has occurred **refer to local hospital neonatal checklist following the death of a baby (see example below)**
- Document this in notes or on local checklists
- Ensure any pending appointments or referrals are cancelled
- **Follow local guidelines** for notifying child death and completion of form A and B for death reviews (legal requirement)

CHECKLIST FOR COMPLETION OF DOCUMENTATION AND NOTIFICATION FOLLOWING DEATH OF A BABY

Attach patient label

Name of nurse caring for baby at time of death: _____
Care handed over to: _____

	DATE	SIGN AND PRINT NAME	COMMENTS
Baby and family			
Take 3 photographs and offer 2 of them to the parents in the Memories folder. If parents decline photographs, place in notes and inform parents that this has been done			
Seek permission from parents to obtain foot/hand prints and place in Memories folder			
Place Memories folder in envelope provided and give to parents			
Provide relevant literature. Document leaflets given in comments column			
Notify chaplain or other religious representative if parents wish. Inform parents of memorial services and date			

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if appropriate			
Involve parents in preparation of the body (last offices) as much as they wish, with respect to cultural practices. [Care after death in hospital (last offices) policy].			
Medical Certificate Doctor signing the certificate should print name alongside signature and GMC number. Place certificate in envelope provided and give to parents. If post mortem is required the medical certificate will be issued after the post mortem is complete			
Complete the 'IV lines removed or in-situ' sticker, and place in the medical notes			
Mortuary documentation			
Notice of Death Attach white copy to shroud. Place yellow copy in the medical notes. The pink copy to go in the bereavement box			
Release of the body form Complete the relevant section and send with baby to the mortuary			
Rapid registration of birth and death (Weekends and Bank Holidays, except Christmas day, Easter Sunday and Good Friday). Contact the local Birth and deaths			
Blue funeral request form Complete the form and ask the mother to sign. Send with the baby to the mortuary			
Cremation Certificate To be signed by 2 doctors. To be send to the mortuary with the baby			
Clinical information for fetal/perinatal post mortem To be completed if for post mortem. Attach to the post mortem forms and send to the mortuary with the baby			
Post mortem or Coroner's referral			
Post mortem forms Informed consent must be obtained for full or partial post mortem. Place white copy in the medical notes. The blue copy is sent with the baby to the mortuary. Yellow copy is given to the parents. In addition send 'release of the body' and hospital funeral form with the baby for post mortem. All admissions to the Neonatal Unit require the placenta to be sent to the			

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mortuary. To be kept for 1 month. Midwives to complete the documentation.			
Coroners A copy of the medical notes needs to be sent with the baby to the mortuary			
Inform registry office Contact registry office informing them that a baby has gone for PM/Coroners. Provide details of name, date of birth, date of death, mothers name and contact number. State that the parents are aware to contact them when medical certificate is available			
Database			
MBRRACE-UK (database) Specialist Midwife for Clinical Governance and Risk, and Lead Midwife for Risk need to be notified			
OASIS system to be amended by the appropriate ward clerk			
Enter baby details onto BADGER database and print 6 copies of the notification letter. Send copies to: <ul style="list-style-type: none"> • GP • Community midwives (if baby under 28 days of life) • Health visitor • Obstetric secretary • Medical notes • Social services (if applicable) 			
Complete congenital anomaly section on BADGER database if applicable			
Babies with confirmed congenital anomalies complete WMCAR form NNU place copy in medical notes and send original to WMCAR in pre-paid envelope. Maternity Unit and send to Specialist midwife Screening Co-ordinator, ANC			
Complete DATIX incident form. Document the automatic issue number in the comments box			
Notifications			
Notify GP by telephone. Also complete GP notification form. Top copy to remain in book, second copy to be posted to GP			
Telephone Community midwives – if baby under 28 days of age			
Telephone Health visitor			
Complete Child Health Department			

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notification form and send as well as confirming receipt.			
Send Badger letter to Child Death Review Co-ordinator at Safeguarding and Review Service,			
Email			
Matron for Paediatrics and Neonates			
Baby's named Consultant and their secretary			
Obstetric Consultant and their secretary			
Child death Review Co-ordinator			
Specialist Midwife for Clinical Governance/Risk			
Register.office if for PM/coroners)			
Records			
Enter details in admission book including date and time of birth and death			
Complete Bounty suppression form and place in envelope on obstetric unit			
Inform pharmacy to cancel TPN (if receiving)			
Send notes to baby's named Consultant Paediatric Secretary when documentation complete			
Parents who wish to take their baby home			
Medical certificate must be completed			
Release of body form must be completed and given to the parents			
Funeral request form completed and given to the parents			
Nurse/Midwife must contact the local police informing them the parents will be transporting the deceased baby in their car/vehicle			
Contact Rapid registration of birth and death (Weekends and Bank Holidays, except Christmas day, Easter Sunday and Good Friday). Contact local Births and Deaths			
Advise parents that they should inform their mortgage lender if they wish to bury the baby on their home premises			
Advise parents that local authority legislation is in place that governs the safe and sanitary disposal of the body			