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 an unwell 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 in detail
- 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 https://adc.bmj.com/content/100/Suppl_2/
- If appropriate and local policy, review baby for organ donation
- discuss with organ donation team before approaching parents
- further guidance available via https://www.odt.nhs.uk/deceased-donation/best-practice-guidance/paediatric-care/
- If organ donation not appropriate or considered, then ask parents if they wish a religious or spiritual person to be involved
- Complete the West Midlands Neonatal Operational Delivery Network Integrated Comfort Care Pathway (ICCP) https://www.teamwmcn.nhs.uk/neonatal-guidelines. This document:
- acts as a record of events and a guide for palliative care
- contains useful links for further information
- Complete ReSPECT form – can work in conjunction with any advanced care plans
- If transfer home or to a hospice, complete advance care plan, as dictated by local team/hospice
- If death is sudden and unexplained, follow sudden unexpected death in childhood (SUDIC) guidelines and consult with on-call SUDIC consultant where necessary West Midlands Safeguarding Children Group (procedures.org.uk)

Second opinion when withdrawal of care not agreed

- If there is disagreement amongst the MDT 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

Saying goodbye

- Consider an appropriate place of care for baby, including transfer to a hospice if available/appropriate and parents' preference
- Parents may request a blessing or ceremony by a religious representative or family member
- Ensure all family members are allowed time and privacy with baby
- Offer parents an opportunity to take photographs of baby if they wish

- Provide a keep-sake box that can include photos, hand and footprints, lock of hair, cot card, etc.
- 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 (if trained to do so) 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 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 (see The SUDIC Protocol - RCEMLearning)
- If birth has not been registered confirm with parents what this will be and ensure that it appears on all subsequent documentation (including death certificate, if issued)

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
- 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

- Offer a post-mortem in all babies not requiring investigation by the Coroner. It is the 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
- Post-mortem request must come from tier 2 staff /consultant 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 tier 2 staff/consultant 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 baby on the NNU if possible or chapel of rest

- Unless the Coroner is involved, parents may take baby's body directly from the NNU, once appropriate documentation has been completed (see SANDS website – www.sands.org.uk/). Where babies are taken will depend upon religious belief of parents or on whom they have designated as 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 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. (See **Death guideline checklist** https://www.teamwmcn.nhs.uk/neonatal-guidelines
- 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)