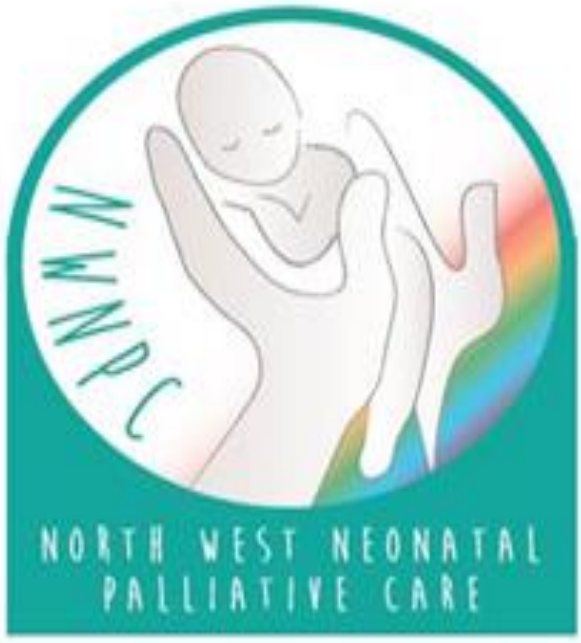
# North West Perinatal/Neonatal Palliative Care

# Non-viable or Pre Viable Births Including Live Birth Following Termination of Pregnancy




*"There is no footprint so small, that it does not leave an imprint on this world"*

**This guideline has been produced in partnership with the Northwest Paediatric Palliative Care Network**

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# Non-viable or Pre Viable Births Including Live Birth Following Termination of Pregnancy

## Introduction

- *The role of guidelines is to offer a pattern of care for clinicians particularly those less experienced, when faced with difficult decisions at times when immediate action may be required*. No guidance covers every eventuality and can never be a substitute for carefully considered, confirmed, forward planning between parents and senior clinicians. This guidance has been developed to assist in the difficult situation of a non-viable baby, including live-born infant following termination of pregnancy. Between1996-2001, 31 infants were live-born following Termination (N.W CESDI database). Feticide can be distressing to parents, and live-birth following TOP has ethical and legal implications for Midwives, Obstetricians and Paediatricians.(1)

## Communication before Delivery

- Good communication between the parents and all health care professionals involved is of primary importance.
- The most experienced clinician (Obstetrician) available at the time (together with the bereavement advisor) should agree a provisional plan with the parents based on clinical information and up to date outcome data. If possible, time should be allowed for all to consider the information and options available. **If appropriate** inform the neonatal consultant on duty, who should be involved with counselling of late termination if the mother has refused foeticide.
- Management plan should be **clearly** recorded in the notes and be accessible to all clinical staff.
- Decisions on management if the baby is born alive, should be based on what is perceived by the parents and their medical advisors to be in the child's best interests, uninfluenced by the child's gender or by religious, eugenic, demographic or financial factors. (Human Rights Act 1998.Appendix 1)

## Management of Live Born Infant Under 22 Weeks

Parents should be counselled that:

- Their baby may be born alive and move and gasp.
- If the infant is regularly breathing with a heartbeat present the senior midwife/obstetrician should be called to assess the infant.
- <22 weeks, it is extremely unlikely a baby will survive labour following cervagem.[10]
- Women should be counseled that there is a slight possibility the baby will be born with a heart beat and may move or gasp, but that no action will be taken and survival at this gestation is not possible.[10]

- Comfort care (warmth, oral nourishment, treated with respect, dignity and love)[7] will be offered, unless gestation is felt to be considerably more advanced than anticipated. Wrap baby, give to family/carer to hold. Moses basket can be obtained in different sizes.
- After assessment by senior midwife and discussion with obstetric consultant, further advice from the neonatal consultant may be sought in order to support parents and health care team .

## Management of Live Born Infant over 22 Weeks (where foeticide has not been performed)

- There are a number of situations where termination may be performed at higher gestations for lethal conditions, where foeticide is refused by the families, or not offered (anencephaly, bilateral renal agenesis, lethal skeletal dysplasia, limb body wall syndrome.) [10]
- In these situations the senior neonatal team should be involved and a clear palliative care plan agreed.
- Parents should be counseled that the baby may be born alive and move and gasp.
- If the infant is regularly breathing with a heartbeat present the neonatal team will be aware and a palliative care plan should be in place [11]
- After assessment by a senior midwife, the neonatal team might attend delivery, if previously agreed to be appropriate by the neonatal consultant, in order to support parents and health care team, and confirm maturity and viability of the infant.
- Comfort care according to agreed plan[11] (warmth, oral nourishment, treated with respect, dignity and love)[7] will be offered, Wrap baby, give to family/carer to hold. Moses baskets can be obtained in different sizes.

## Ethical Considerations

When agreement between parents and clinical staff cannot be reached over management after birth, provisional intensive care could be offered pending further assessment and discussion if gestation was felt to be considerably in advance of 22 weeks.
When intensive care is withheld or withdrawn, use of opiates may be entirely appropriate.
Once delivered, the Paediatrician has a duty to ensure that the baby undergoes no undue suffering nor should survival be at the cost of long-term handicap.

## Other Points

All cases should be thoroughly investigated to look for causes, using the normal medical investigation protocol. All babies born alive, **regardless of gestational age**, need to be registered as live births and subsequently registered as a neonatal death, live births following termination, and in Greater Manchester, all deaths under 18years, need to be discussed with the coroner. Therefore the appropriate documentation should be completed. Usually, by the obstetric team, but if neonatal team involved, by them.

**1** Birth Notification (including early NND tick appropriate box on form)
**2** Death certificate
**3** MBBRACE notification

Bereavement counselling should be offered via one of the bereavement midwives.

## Human Rights Act 1998

Once a baby has been born alive, it acquires legal rights and therefore a right to life. This is provided for in Article 2 of the European Convention on Human Rights that states, 'Everyone's right to life shall be protected by law. No one shall be deprived of his life intentionally…' Article 2 is incorporated into the law of England, Scotland Wales and Northern island by way of the Human Rights Act 1998.

## Live Birth

Definition: A child born alive.

## WHO 1992

' a live birth is the complete expulsion or extraction from its mother of a product of conception, irrespective of the duration of pregnancy, which, after such separation, breathes or shows any other evidence of life, such as beating of the heart, pulsation of the umbilical cord, or any definite movement of the voluntary muscles, whether or not the umbilical cord has been cut or the placenta is attached.

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