

Perinatal Palliative Care Framework MCN (South East Scotland)

Background

In 2010 British Association of Perinatal Medicine published Palliative care (supportive and end-of-life care) A Framework for Clinical Practice in Perinatal Medicine.

The key components of the framework include:

- Decisions about perinatal end of life care planning should be based on the best possible information on the diagnosis and prognosis of the underlying condition.
- Palliative care should only be considered if the fetus or baby has a candidate condition.
- If a woman decides to continue her pregnancy knowing that her baby has a condition that will cause significant disability but is non lethal, the baby is not necessarily eligible for palliative care.
- Joint decision making with parents, open communication and clear documentation are essential for good decision making and the delivery of the care plan.
- An individualised integrated care plan should be drawn up after multidisciplinary discussions between clinical specialists, the parents and the team that will provide palliative care. Antenatal and postnatal care of the mother need to be included in the care plan.
- The care plan should cover all foreseeable outcomes. It should be flexible enough to allow for changes in the condition of the mother or the baby and in the parents' views and wishes

Also in 2010, ACT (now Together for Short Lives) published A Neonatal Pathway for Babies with Palliative Care Needs. This pathway aims to draw together the professionals and resources needed to accompany the baby and family along their unique care journey. It has been written for professionals and commissioners of services to ensure that the appropriate care and resources are available in the right place, at the right time for each of these babies. It is an integrated care pathway to support professionals working in maternity and obstetric services, neonatal and children's services as they care for young babies who have life-threatening or life-limiting conditions

Gap

- There is a need for a unified pathway incorporating existing guidance that supports best practice for clinicians when establishing eligibility for and delivering palliative care for babies during the antenatal and postnatal periods

Aim

This draft framework aims to ensure that there are recognised pathways of palliative care for a baby within and between fetal medicine, maternity, neonatal units and other services for every baby who has a life-limiting/life-threatening condition. The framework sets out key goals and standards to be achieved for best care and the most appropriate staff to deliver care. It also describes key training required and potential process to audit the standards

We recognise that these pathways need to be discussed and aligned with other care pathways being developed by other health care and external agencies, but offer this version as a model to base the development of more localised pathways on in the future. The care of babies and their families involves a range of services and agencies and a number of professionals.

Perinatal palliative team

The pathway has been developed with a “perinatal palliative team” as part of the framework. It is envisaged that a lead nurse, neonatologist or paediatrician and staff link from CHAS would act as the perinatal palliative team for the MCN (SES)

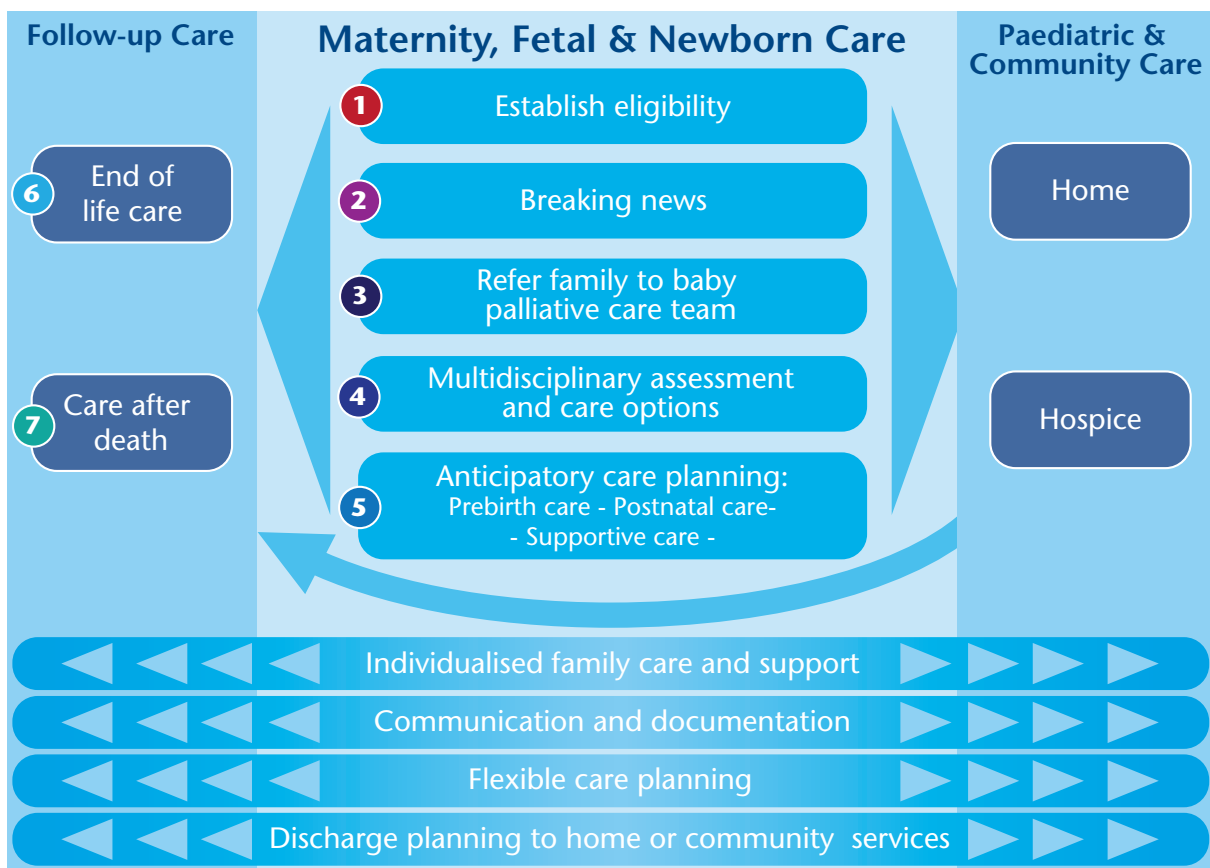
Further development

It is anticipated that a standardised Audit tool and education and training programme will be developed to support the pathway.

Consultation

The authors of this draft welcome your input and comment on this work and a series of consultation questions are included in Appendix 8

Goals of perinatal palliative care pathway



1. Establishing eligibility

Discussions about a fetus or baby's eligibility for palliative care and the subsequent planning of their care should be based on the best possible information on the diagnosis and prognosis of their underlying condition. *See Appendix 1*

Standards of clinical care

- A Consultant in Obstetrics and Fetal medicine should reach an agreement on the diagnosis and prognosis of the underlying condition of the fetus
- A Consultant in Neonatology, or Paediatrics should reach an agreement on the diagnosis and prognosis of the underlying condition of the baby
- Based on this information the lead consultants make a decision if the baby's condition before or after birth is eligible for palliative care
- Lead consultants have initial discussion about palliative care planning options for the baby and family (including antenatal and postnatal periods)
- Multidisciplinary meetings and or a second consultant should be involved in the decision making process
- Lead consultants should document and communicate decision making with hospital clinicians and community team at both local and referring centre
- Inform the perinatal palliative care team of the baby and family for information only

2. Breaking news

Every family should receive the disclosure of their baby's prognosis in a face-to-face discussion in privacy and should be treated with respect, honesty and sensitivity. Information should be provided for the family using language that they can understand.

Standards of clinical care

- This discussion should be led by the most senior clinician available, ideally the lead consultant involved in agreeing eligibility for palliative care
- Is news shared in a face to face discussion in privacy
- If the fetus has a condition that is life limiting, a woman should be offered the choice of continuing a pregnancy with planned palliative care
- Has useful information e.g. support organisation leaflets been provided to family
- Agree with parents if they wish the fetus or baby to receive palliative care
- Advise family that a referral will be made to the perinatal palliative team
- Lead consultants should document and communicate the outcome of breaking news to the family. Communicate whether the family wish to consider palliative care planning at this stage. Document and communicate this with hospital clinicians and community team at both local and referring centre

3. Referral to baby palliative team

Every family should receive personalised, realistic care options which takes into account their baby's and wider family's needs developed by key personnel including hospital, community services and hospice services. *See Appendix 2*

Standards of clinical care

- Referral of the baby and family to the perinatal palliative team should be made within 48 hours of breaking news to the family
- Perinatal palliative team and lead clinicians to identify and document core membership of the baby's key working team
- Team will identify the lead professional for communications with the family
- Perinatal palliative team to identify appropriate multiagency staff to be involved
- Agree timing of multidisciplinary assessment (by maximum of 10 working days of referral)
- Local lead clinicians to update parents on progress
- Document and communicate referral with hospital clinicians and community team at both local and referring centre

4. Multidisciplinary assessment of care options and family's needs

Every family should receive a multi-agency assessment of their needs as soon as possible after their baby's diagnosis or recognition that their baby's condition is life-threatening or life-limiting. They should have their needs reviewed at appropriate intervals.

Standards of clinical care

- Face to face or tele linked meeting with palliative care team, local clinicians and relevant staff
- Identify the baby's care options
- Assign roles to members of the key working team
- Agree provisional care timeline
- Local clinician to update parents on progress
- Has discharge planning commenced if appropriate
- Document and communicate MDA care options with hospital clinicians and community team at both local and referring centre

5. Anticipatory palliative care planning with the family

Every baby and family should have a multi-agency anticipatory care plan agreed with them for the delivery of co-ordinated care and support to meet their individual needs. A lead clinician to assist with this should be identified and agreed with the family. *See Appendix 3*

Standards of clinical care

- Discuss and agree as many of the points of the care plan sensitively including care at end of life and care after death (see appendices)
- Is the use of a CYPADM form indicated at this stage
- What is the parent's preferred place for their baby's death?
- Update parents on progress and explain the care plan will be continually reviewed with them
- Explain to parents that they will be informed when the baby is probably approaching its end of life
- Document and communicate discussions and agreed components of the palliative care plan. Communicate to the relevant staff, including hospital clinicians and community team at both local and referring centre

6. End of life care planning

Every family should be helped to prepare an end-of-life plan for their baby and should be provided with care and support to achieve this. *See Appendix 4*

Standards of clinical care

- Has a senior clinician explained to the family that the baby is probably approaching its end of life
- Has joint planning with the family and relevant professionals taken place?
- Have points of end of care plan been reviewed and agreed (see appendices)
- Document and communicate discussions and agreed components of the end of life and care after death plan. Communicate to the relevant staff, including hospital clinicians and community team at both local and referring centre

7. Care after death

Bereavement support should be provided along the care pathway and continue throughout the baby's death and beyond. *See Appendix 5*

Standards of clinical care

- Have points of the care after death plan been discussed and agreed with the family
- Are parents aware of their choices in caring for their baby's body
- Has death been confirmed and death certificate completed
- Has a senior clinician discussed the death certificate with the family?
- Have parents been given details of how to register their baby's birth and death?
- Have the bereavement needs of the parents and siblings been assessed?
- Have parents been told about medical and bereavement follow up?
- Has the baby's death been communicated to relevant professionals and agencies (verbally and or written within 24 hours)
- Has staff support been addressed?
- Has a date been set for a staff debrief?
- Document and communicate discussions and agreed components of the end of life and care after death plan. Communicate to the relevant staff, including hospital clinicians and community team at both local and referring centre

Appendix 1

Establishing eligibility of a baby for palliative care before or after birth

It can be helpful to consider these 5 broad categories to aid decision making:

1. An antenatal or postnatal diagnosis of a condition which is not compatible with long term survival, e.g. bilateral renal agenesis or anencephaly.
2. An antenatal or postnatal diagnosis of a condition which carries a high risk of significant morbidity or death, e.g. severe bilateral hydronephrosis and impaired renal function.
3. Babies born at the margins of viability, where intensive care has been deemed inappropriate.
4. Postnatal clinical conditions with a high risk of severe impairment of quality of life and the baby is receiving life support or may at some point require life support, e.g. severe hypoxic ischemic encephalopathy
5. Postnatal conditions which result in the baby experiencing “unbearable suffering” in the course of their illness or treatment

Antenatal diagnosis and establishing eligibility

- Antenatal diagnosis of a structural abnormality should be confirmed by a fetal medicine consultant
- Consider using other modes of investigation eg MRI, genetic testing to confirm diagnosis or add further information
- Cardiac anomalies should be assessed by a perinatal cardiologist using fetal specialist echocardiography
- Investigations should be followed by a multidisciplinary team (MDT) discussion to agree the diagnosis and prognosis. This is not essential in fetal conditions for which there are simple definitive diagnostic tests and an agreed prognosis, e.g. anencephaly
- The team should consider if the diagnosis has any implications for maternal health eg anencephaly and polyhydramnios
- The information on diagnosis and prognosis should be communicated to the parents and the lead clinicians at both specialist and local referring units, GP and community midwifery team
- In Categories 1 and 2, both the option of continuing the pregnancy with palliative care and the option of terminating the pregnancy should be discussed with the parents. These discussions are usually held with the fetal medicine team
- It is important to note that not all pregnancies which fulfil the criteria for late termination of pregnancy under section E of the Abortion Act, would be suitable for palliative care.
- Communication aids such as video conferencing and video telemetry in real time should be considered when the specialist unit and the referring unit are in different localities
- If either the parents or members of staff are still uncertain about the diagnosis or prognosis, a second opinion, either internal or external, should be sought

Postnatal diagnosis and establishing eligibility

The prognosis for the baby should be agreed by at least two consultant paediatricians/ neonatologists. These may be internal or external second opinions, depending on the unit's referral pathways. An MDT meeting should be considered if there is uncertainty about the prognosis, or if further opinions from other disciplines (e.g. paediatric neurology) are required.

Appendix 2

Referral to perinatal palliative team

- Make the referral to perinatal palliative team for the network. This will be a named nurse, consultant paediatrician/neonatologist and representative from CHAS. They may not be working on your local unit. Their responsibility is to work with the local lead clinicians responsible for the baby and family to ensure that the goals and standards of the pathway are met.
- The perinatal palliative team are responsible for ensuring that the most appropriate community professionals are part of the MDT discussions and planning
- The perinatal palliative team are responsible for ensuring that the discharge process in to the community is optimal

Appendix 3

Anticipatory care planning – Pre birth planning

- Routine antenatal care should continue if a palliative care plan is being developed with the family
- **Multiple pregnancy:** In cases of multiple pregnancy individualised care plans should be drawn up for each baby
- **Birth plan:** Mothers should be encouraged to discuss their wishes for labour and birth before preparing a birth plan. In general, the aim should be to wait for spontaneous labour and to avoid unnecessary intervention.

An explicit care plan should be developed with the mother including:

- The place of fetal monitoring (not usually recommended)
- Action to be taken in the event of fetal distress

Mode and conduct of delivery

- **Caesarean section:** may be indicated if labour increases risks to the mother. A mother may request a Caesarean section to increase chances of baby living for a brief time (second counselling)
- **Place of delivery:** Explore options of place of delivery. Local unit, regional unit or home birth
- **Delivery room:** Consider privacy and emotional needs when identifying a delivery room
- **Staff at delivery:** Consider and specify members of staff that need to be present or available at delivery
- **Resuscitation at delivery:** Non resuscitation or limitations to resuscitation should be discussed and reviewed on a regular basis
- **Postnatal care of the baby:** How baby will be handled and cared for after delivery
- **Rapid postnatal assessment:** Is a rapid assessment by a senior paediatrician/neonatologist needed to confirm a candidate condition for palliative care.
- **Rapid postnatal investigations:** Occasionally, specific tests may be helpful, e.g. rapid karyotype of cord blood in the case of anomalies suggestive of a lethal aneuploidy.
- **Postnatal care of the mother:** It is important to remember that routine postnatal care of the mother should continue if the baby has a palliative care plan

Appendix 3 continued

Anticipatory care planning – Transition from active postnatal care to supportive care

In some cases there is likely to be a gradual transition from active care in to palliative care. Active treatment and monitoring may be continued during the period while parents and staff re evaluate what serves the best interest of the baby. There may need to be a consideration of the length of time of the transition phase so the baby's interests are maintained

Anticipatory care planning – Supportive care

Physical comfort care

- Continue to practice basic care of positioning, skin care, mouth care, skin to skin contact

Pain relief

- Assess and treat any underlying causes of pain
- Use analgesia as guided by CBNF and symptom control manual

Nutrition and feeding

The goal of feeding is to provide comfort and reduce distress from hunger with growth as a secondary outcome. Parenteral fluids, nutrition and nasogastric tube feeding are rarely indicated. Route of feeding should be what is most suitable for baby. Breast feeding may be comforting for the baby and mother. It may not be possible to maintain hydration

- Agree the goals and route of nutrition and feeding and the type of milk and fluids. This should be frequently reviewed and documented
- **Vomiting:** consider reducing feeds or using anti reflux treatment if symptomatic
- **Constipation:** If causing distress consider using lactulose or glycerine suppositories
- **Urinary retention:** consider abdominal pressure and rarely catheterisation
- **Elimination needs:** consider stoma care, stoma team support and any equipment required

Resuscitation plans

Limitations to resuscitation should be discussed and reviewed regularly. Comfort and dignity of the baby should be maintained. Consider the potential suffering and loss of dignity for a baby that prolonged resuscitation or ventilation can lead to:

- **Respiratory secretions:** should be treated if distressing to the baby. Consider use of hyoscine patches
- **Resuscitation plans discussed and documented:** These should be reviewed regularly and the CYPADM form updated

Investigations monitoring and treatment

Monitoring is not necessary, but may be used if helpful for parents. Investigations should only be performed if the results might lead to treatment that will improve the baby's quality of life or help with the diagnosis and management of subsequent pregnancies. Treatments such as antibiotics, oxygen, anticonvulsants, anti reflux medication, insertion of rickham reservoir or VP shunts, hernia repair can have a role in symptom control. Immunisations should be given as per national immunisation programme

- Agree goals of monitoring, investigations and treatment. Review these regularly and document in medical records

Appendix 4

End of life care

- **Transition to end of life:** It is important to agree the care plan from active or supportive care to end of life care. This should be explained to the staff and families e.g. how and when an ET tube and intravenous canulae are removed, and monitoring leads disconnected
- **Place of care:** Depending on the situation and the level of supportive and end-of-life care required, the baby may die in utero, on the delivery suite, in a postnatal ward, the neonatal unit, at home or in a children's hospice. The lead paediatrician or neonatologist should discuss with the parents where the baby will be cared for, explain what is likely to happen, and take their wishes into account as far as possible. If a baby is being discharged home, or to a children's hospice for supportive and end-of-life care, the health of the mother must also be considered and suitable practical and emotional support arranged as needed.
- Has care of mother been considered if baby being discharged home
- **Staff leading end of life care:** The staff who will be responsible for managing this period should be identified in advance

Physical changes in appearance

Physical changes that are likely to occur as a baby dies should be discussed with the family and whether families want to see and hold their baby whilst he or she dies and/or after death. Terminal gasping should be explained in order to reassure parents that this is not an indication of suffering and usually not treated. Parents should be made aware that the time until death can vary from minutes to hours and possibly days.

- **Organ donation:** If relevant, the parents should be told about the option of organ donation (e.g. heart valves) although this would clearly depend on the absence of any congenital anomaly in the donate tissue.
- **Post mortem:** A senior member of staff should sensitively encourage the parents to consent to a post-mortem investigation and examination so that maximum information can be obtained. In some cases it may be appropriate to discuss this sensitively in the antenatal period.

Appendix 5

Post death care

- **Confirmation of death Certification of death:** If a baby is born with signs of life before 24 weeks, is stillborn at or after 24 weeks, or is born alive and subsequently dies, the parents must register the stillbirth or birth and death. do this. Certificate' for live born infants.
- Parents should be given both verbal and written information about how and where to register the birth and death
- A plan should be in place to identify the doctor who will sign the "Cause of Death". This has to be a doctor who has seen the baby alive and is certain about the cause of death.
- It would be advisable to talk to the coroner if the doctor has not seen the child prior to death or within 14 days of death.

Appendix 5 continued

- The care plan should indicate who and when to inform when a baby dies at home. When an expected death occurs at home, there is no urgency for the family to call a doctor. The care plan is particularly important at this point and parents should keep a copy of the care plan at their home.
- **Taking a deceased baby home:** Parents can take the remains or body of their baby out of the hospital at any gestation. Staff should give parents some documentation to take with their baby's body. Sample forms for this purpose can be downloaded from the Sands website: www.uk-sands.org/Improving-Care/Resources-for-health-professionals/Forms-and-certificates-to-download.htm

Funeral (burial or cremation)

The options for a funeral and how this can be organised should be sensitively discussed with the family.

General

Communication and documentation

The responsibility of care may be passed from regional to local units, and to the community. Written care plans should be in plain English or appropriate translation and all medical terms should be explained clearly so that parents will understand them. Parents should receive all information documented in hand held notes. The care plan may need to be altered to allow for changes in the place of care, the condition of the mother or the baby and the parents' views and wishes. Consider alert systems (e.g. SANDS teardrop sticker) with parental consent to help identify families to clinical and administrative staff.

- **Timing of discussions:** Discussions and decision making may be taken during the antenatal period, at birth or at any time after birth.
- **Primary care team:** It is vital to involve or inform members of the primary care team about palliative care planning as soon as possible: GP, children's community nursing team, health visitor, paediatric palliative care team and children's hospice, if appropriate, as they may be part of the team delivering palliative care.
- **Key member of staff:** At all times the parents should have the name and contact details of a key member of staff (recorded on the care plan) and staff covering them when on leave.
- **Place of conversations:** Consideration should be given to the location of meetings between parents and professionals and, in particular, the area in which parents will have to wait beforehand. Parents should have a choice whether to wait in antenatal clinics or paediatric clinics with families who are experiencing uncomplicated pregnancies or have children with them, or have more privacy

Individualised family care and support

- **Psychological support:** Staff should consider whether the family including siblings should be offered the opportunity to see a trained counsellor / bereavement counsellor. General practitioners, the primary care team and paediatric palliative care team may also be helpful in providing general support, symptom relief and referral for specialist counselling.

- **Creating memories:** Many parents will also be grateful if staff explain and facilitate the option to create and collect mementoes. These might include antenatal scan pictures, photographs, foot and hand prints, a lock of hair, clothes the baby has worn, cot tags, identity bracelets certificates and copies of consent forms.
- **Support of spiritual/personal belief:** Care should reflect parents' personal and/or spiritual wishes. Staff should ask parents sensitively what they would like and, where appropriate, help to organise this.
- **Social support:** Parking and restaurant discounts are available at some hospitals. Parents should be guided to information about benefits and maternity and paternity rights. Staff should ensure that mothers know that they must apply for benefits within three months of the baby's birth. Specific needs for social support should be discussed at each stage.

Discharge planning to home or community services

- The place of discharge to the community should be a constant consideration
- Transport should be organised to allow time at home or the hospice prior to the period of end of life care.

Flexible care planning

Whilst there are many conditions where there is reasonable certainty of death during fetal and neonatal life, there are babies who survive longer than expected during supportive and end-of-life care. It is vital that all care planning is continuously reviewed in the best interests of the baby. There should be parallel planning for transition periods into and out of active, supportive and end-of-life care.

Consultation

Resources

- British Association of Perinatal Medicine Palliative care (supportive and end of life care)
A framework for clinical practice in Perinatal medicine
- Paediatric Resuscitation Policy for Scotland
www.scotland.gov.uk/Topics/Health/NHSScotland/LivingandDyingWell/CYPADM/CYPADMPolicydocument
- Living and Dying Well: An Action Plan for palliative and end of life care in Scotland" September 2009 Scottish Government www.scotland.gov.uk/Topics/Health/NHSScotland/LivingandDyingWell
- Living and Dying Well: Building on Progress" January 2011 Scottish Government www.scotland.gov.uk/Topics/Health/NHSScotland/LivingandDyingWell/buildingonsuccess
- The Management of Babies born Extremely Preterm at less than 26 weeks of gestation British Association of Perinatal Medicine.
- Withholding or Withdrawing Life Sustaining Treatment in Children – A Framework for Practice. Royal College of Paediatrics and Child Health, 2nd Ed. May 2004.
- Shaping Bereavement Care (Scottish Government, 2010).
- MCN for children with exception health care needs: www.cen.scot.nhs.uk/
- Together for Short Lives A Neonatal Pathway for Babies with Palliative Care Needs 2009 www.togetherforshortlives.org.uk
- A Framework for Clinical Practice at the time of Birth. Arch Dis Child FNN Online October 6, 2008 as 10.1136/adc.2008.143321

- Together for Short Lives The Guide to the Development of Children's Palliative Care Services 3rd Edition 2009 www.togetherforshortlives.org.uk
- Bliss (2007) Financial help for families Downloadable from Bliss Publications, www.bliss.org.uk
- Pregnancy Loss and the Death of a Baby: Sands Guidelines for Professionals. J Schott, A Henley, N Kohner, Sands, 2007
- Rainbows Children's Hospice, 2012. (due imminently) Basic Symptom Control in Paediatric Palliative Care. 8th Ed. Rainbows Children's Hospice.

MCN SES Perinatal Palliative Care Pathway Consultation Response

This form should be completed and submitted to:

WHO: Edile Murdoch, Consultant Neonatologist

WHERE: edile.murdoch@nhslothian.scot.nhs.uk

Room S5114, Department of Neonatology, Simpson's Centre for Reproductive Health, Royal Infirmary of Edinburgh, 51 Little France Crescent, Edinburgh, EH16 5SA.

WHEN: By November 30th 2012

Goal 1 STATE

Please provide views on this goal for neonatal palliative care. Do you think that the standards are achievable?

Goal 2 STATE

Please provide views on this goal for neonatal palliative care. Do you think that the standards are achievable?

Goal 3 STATE

Please provide views on this goal for neonatal palliative care. Do you think that the standards are achievable?

Goal 4 STATE

Please provide views on this goal for neonatal palliative care. Do you think that the standards are achievable?

Goal 5 STATE

Please provide views on this goal for neonatal palliative care. Do you think that the standards are achievable?

Continued over →

MCN SES Perinatal Palliative Care Pathway Consultation Response

Goal 6 STATE

Please provide views on this goal for neonatal palliative care. Do you think that the standards are achievable?

Goal 7 STATE

Please provide views on this goal for neonatal palliative care. Do you think that the standards are achievable?

1. Standards of care

Do you support an outcomes focussed, standards based approach?

Do you agree with the range of goals and standards identified?

Are any missing?

Other comments/detailed views on the standards?

Name:

Date:

Job Title:

Are you replying on behalf of an organisation?

Yes/No

If yes, which organisation: