Goals and standards of care for perinatal palliative care  
MCN Neonatology (South East Scotland and Tayside)

Vision
Develop a national good practice framework for perinatal palliative care to accompany the Framework for the Delivery of Palliative Care for Children and Young People in Scotland.

Background
Palliative care during the antenatal and early postnatal period is a growing challenge with the advances in fetal medicine and neonatal care. There are more than 100 babies in Scotland who die each year during the neonatal period. It is therefore important to have a unified framework for care incorporating existing guidance that supports best practice for clinicians when establishing palliative needs and delivering palliative care for babies during the antenatal and postnatal periods.

Aim
This document provides key goals and standards for the delivery of perinatal palliative care, supported by important points of care. The focus of this guide is the baby who has a life-limiting/life-threatening condition in the antenatal or postnatal period. The goals and standards will incorporate the transition of a baby and their family within and between maternity, neonatal, paediatric, community services and home. This framework is intended to be adapted for local use according to local protocols, resources and circumstances.

Journey
This framework has been subject to national consultation including parents, statutory and voluntary organisations and the Neonatal Managed Clinical Network (MCN).

Future
This framework of goals and standards will be piloted in NHS Lothian. It has been developed with a perinatal palliative support (PPS) team as part of care delivery. This team has local responsibility to support professionals in the delivery of palliative care and establish performance indicators, quality standards and audit. In NHS Lothian the team consists of:

- Neonatal/Paediatric Nurse
- Neonatologist
- Community paediatrician
- Link staff from Children’s Hospice services

During the pilot, quality and performance indicators will be evaluated and education and training needs identified. The pilot will be reported on to NHS Lothian and the MCN for Neonatal Services (SEAT).

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Goals of perinatal palliative care good practice

1. Might this baby have palliative care needs?
   - NOT YET

2. Has an obstetric or a paediatric consultant established whether the baby has palliative care needs?
   - NOT YET

3. Has this news been broken to the family?
   - NOT YET

4. Do the parents wish to consider palliative care at this initial stage?
   - NOT YET

5. Has an initial care plan been established?
   - NOT YET

6. Has a multidisciplinary assessment (MDA) been planned?
   - NOT YET

7. Has an anticipatory care plan been agreed?
   - NOT YET

8. Has an end of life and care after death plan been agreed?
   - NOT YET

Early initiation of discussions about end of life care are helpful

The medical team responsible for care should continue to consider a baby’s possible palliative needs

Palliative care cannot be planned without consensus that a baby has palliative care needs. Revisit this with the medical team responsible for care

Palliative care cannot be delivered until the family understand their baby has palliative care needs.

Continued to revisit these discussions sensitively at appropriate times

Organise the multidisciplinary assessment (MDA) as this needs to take place in order to fully inform staff and family of all care options

There needs to be an agreed care plan so best care is delivered

Have you communicated and documented the outcome of discussions at each stage to parents and all relevant staff?

Have you reviewed whether the baby’s palliative care needs have changed?

Have you considered the comprehensive needs of the baby and family (psychological, social, spiritual, bereavement care)?

Have you considered if the baby needs to be transitioned to another service?
Ongoing care should be delivered throughout the journey of a baby with palliative care needs (see page 11)

Guide to important points of care on this journey

1 Care Goal: Identify palliative care needs

A baby’s potential palliative care needs should be identified at the earliest possible stage and continually reviewed.

Standard of clinical care:
• A baby (fetal or postnatal period) being looked after in obstetric, paediatric or primary care services should have their overall needs reviewed by professionals on a regular basis including any developing palliative care needs

Important points of care:
• Professionals working in perinatal care should have a foundation knowledge of palliative care
• Consultant (lead professional) should consider a baby’s palliative care needs during routine reviews

2 Care Goal: Agree palliative care needs

Discussions about a fetus or baby’s need 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.

Standard of clinical care:
• A Consultant in Obstetrics and Fetal medicine, Neonatology or Paediatrics should ascertain, confirm and document the information on diagnosis and prognosis of a baby’s condition during either the antenatal or postnatal period
• 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
• Based on this information the Consultant responsible for care should make a decision if the baby has a palliative care need. Multidisciplinary discussion including a second consultant should ideally be part of this decision making process

Important points of care:
• Establishing a baby’s need for palliative care before or after birth

It can be helpful to consider these categories to aid decision making

BAPM: A Framework for Clinical Practice in Perinatal Medicine

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
RCPCH: Withholding or Withdrawing Life Sustaining Treatment in Children – A Framework for Practice

1. The “Brain Dead” Child. In the older child where criteria of brain-stem death are agreed by two practitioners in the usual way it may still be technically feasible to provide basal cardio-respiratory support by means of ventilation and intensive care. It is agreed within the profession that treatment in such circumstances is futile and the withdrawal of current medical treatment is appropriate.

2. The “Permanent Vegetative” State. The child who develops a permanent vegetative state following insults, such as trauma or hypoxia, is reliant on others for all care and does not react or relate with the outside world. It may be appropriate to withdraw or withhold life-sustaining treatment.

3. The “No Chance” Situation. The child has such severe disease that life-sustaining treatment simply delays death without significant alleviation of suffering. Treatment to sustain life is inappropriate.

4. The “No purpose” Situation. Although the patient may be able to survive with treatment, the degree of physical or mental impairment will be so great that it is unreasonable to expect them to bear it.

5. The “Unbearable” Situation. The child and/or family feel that in the face of progressive and irreversible illness further treatment is more than can be borne. They wish to have a particular treatment withdrawn or to refuse further treatment irrespective of the medical opinion that it may be of some benefit.

- Antenatal diagnosis of a structural abnormality should be confirmed by a consultant in fetal medicine.
- Consider using other modes of investigation eg MRI, genetic testing to confirm the diagnosis or add further information.
- Cardiac anomalies should be assessed by a perinatal cardiologist using fetal specialist echocardiography.
- Appropriate investigations should be agreed by a multidisciplinary team (MDT). 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 whether the diagnosis has any implications for maternal health eg polyhydramnios associated with anencephaly.
- In Categories 1 and 2 above the option of continuing the pregnancy with planned palliative care for the baby or terminating the pregnancy should be discussed with the parents. These discussions are usually held with the fetal medicine team. It can be helpful to involve paediatricians at this point.
- Not all babies which fulfil the criteria for late termination of pregnancy under section E of the Abortion Act, have palliative care needs.
- The prognosis for the baby should be agreed by at least two consultant paediatricians/ neonatologists. These may be internal or external second opinions and involve other relevant specialists depending on the unit’s referral pathways. This may not be possible in acute circumstances or required when there is existing agreed guidance e.g. babies born at the margins of viability.
3 Care Goal: Breaking bad news
Every family should receive the news of their baby’s prognosis in a face-to-face discussion in privacy and should be treated with respect, honesty and sensitivity.

Standard of clinical care:
• These discussions are best led by the most senior clinician available, ideally the consultant or consultants involved in agreeing the palliative needs of the baby and a midwife or neonatal nurse
• News is shared in a face-to-face discussion in privacy
• Information should be provided for the family using language that they can understand

4 Care Goal: Parent’s initial wishes
All parents should be supported as they make initial choices about their baby’s need for palliative care.

Standard of clinical care:
• Explore with the parents whether they wish to consider a palliative care plan for their baby at this stage
• Explore whether parents wish involvement of other people (friends, family, religious representatives)
• Continuing a pregnancy with a palliative care agreement as an alternative to late termination should be routinely offered if a fetus has palliative care needs

5 Care Goal: The baby’s initial care plan
Every family should receive personalised, realistic care options taking account of the needs of their baby and wider family developed with key personnel including hospital, community services and Children’s Hospice services.

Standard of clinical care:
• Consider if use of a Children / Young People Acute Deterioration Management (CYPADM) form is indicated at this stage
• Within 48 hours of parent’s deciding their initial wishes, inform Perinatal Palliative Support (PPS) team (if applicable)
• The Consultant responsible for care (and PPS team where appropriate) identify and document care membership of the baby’s palliative care key working team and agree timing of multidisciplinary assessment (MDA)
• The Consultant responsible for care should document and communicate the outcome of parents initial wishes, fetus or baby’s initial care plan and key working group names to the relevant hospital clinicians and community team at both local and referring centres

Important points of care:
This guide has been developed with a perinatal palliative support (PPS) team as part of care delivery. This team has local responsibility to support professionals in the delivery of palliative care and establish performance indicators, quality standards and audit.
In NHS Lothian the team consists of:
• Neonatal/Paediatric Nurse
• Neonatologist
• Community paediatrician
• Link staff from Hospice service
Inform the PPS team of the baby, family and the initial decision and care plan.

The PPS team will support the local clinicians to ensure:

- The most appropriate hospital and community professionals are part of the MDA
- Transition is made to the preferred place of care

**6 Care Goal: Multidisciplinary assessment (MDA) 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.

**Standard of clinical care:**
- The Consultant responsible for care should organise a face to face or tele linked meeting with relevant local lead professionals, PPS team and relevant multiagency staff.
- Identify the baby’s care options and provisional timeline of palliative care needs.
- Assign roles to members of the key working team.
- Document and communicate MDA care options with parents, hospital clinicians and community team at both local and referring centre and PPS team.

**7 Care Goal: 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 named clinician must be identified to assist with this and agree plans with the family.

**Standard 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).
- Consider whether the use of a CYPADM form is indicated at this stage.
- Explore what may be the parent’s preferred place for their baby’s death.
- Explain to parents that this is a flexible care plan that can or may change.
- Explain to parents that they will be informed when the baby is deteriorating and likely to die.
- Document and communicate discussions and agreed components of the palliative care plan to the relevant staff, including hospital clinicians and community team at both local and referring centre.

**Important points of care:**

**Anticipatory care planning – Birth plan**

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. In general, the aim should be to wait for spontaneous labour and to avoid unnecessary monitoring and 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

**Anticipatory care planning – Delivery and resuscitation**

- **Caesarean section**: may be indicated if labour increases risks to the mother. A mother may request a caesarean section to increase the chances of her baby living for a brief time. An opportunity to discuss the risks of a cesarean section with another obstetric consultant should be arranged before the plan is agreed.
- **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 who 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

**Anticipatory care planning – Postnatal Care**

- **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 the baby’s condition for palliative care needs
- **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**: Routine postnatal care of the mother should continue whether or not the baby has a palliative care plan

**Anticipatory care planning – Transition from active postnatal care to supportive and palliative care**

In some cases there is likely to be a gradual transition from active care 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 this transition phase so the baby’s care needs are maintained.

**Anticipatory care planning – Supportive care**

- **Resuscitation plans are discussed and documented**: Limitations to resuscitation should be discussed and reviewed regularly. The 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. Resuscitation plans should be reviewed regularly and the CYPADM form updated
- **Physical comfort care**: Continue the normal care of positioning, skin care, mouth care, skin to skin contact
- **Nutrition and feeding**: The goal of feeding is to provide comfort and reduce distress from hunger with growth as a secondary outcome. Route of feeding should be what is most suitable for baby. Breast feeding may be comforting for the baby and mother. Oral feeding should only be withheld if it is felt that providing it will cause pain and discomfort. If a baby can tolerate oral milk then ongoing nutrition should be assessed in line with the baby’s demands. The care planning around continuing or discontinuing intravenous nutrition and hydration should be regularly reviewed with the family
Review the goals of feeding regularly particularly in a baby with a prolonged period of supportive care. Mothers should be supported in managing ongoing breast milk production when her baby can no longer tolerate feeds. This should include information on donated breast milk.

**Anticipatory care planning – Symptom management**

- **Pain relief:** Assess and treat any underlying causes of pain and or discomfort. Consider referral to the pain team if appropriate and available. Use analgesia as guided by CBNF and symptom control manual. Non pharmacological methods to reduce pain and discomfort should be used in conjunction with analgesic medication.

- **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.

- **Respiratory secretions:** should be treated if distressing to the baby. Consider use of hyoscine patches.

- **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.

8 **Care Goal: 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.*

**Standard of clinical care:**

- The family should be informed that their baby is deteriorating and likely to die.

- Confirm that the end of life care plan is up to date and agreed with parents.

- Document and communicate discussions and agreed components of the end of life care plan and care after death. Communicate to the relevant staff, including hospital clinicians and community team at both local and referring centre.

- Ensure CYPADM form is up to date and relevant.

**Important points of care:**

- **Transition to end of life:** It is important to agree the care plan from active or supportive care to the last days 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.

- **Physical changes in appearance:** Physical changes that are likely to occur as a baby dies should be discussed with the family and changes in breathing should be explained in order to reassure parents that this is not an indication of suffering and does not need treatment.

- **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, postnatal ward, neonatal unit, paediatric ward at home or in a children’s hospice. The lead paediatrician or neonatologist
should discuss with the parents the options of where the baby could be cared for, explain what is likely to happen, and take their wishes into account as far as possible

- **Care of mother**: If a baby is being discharged home, or to a children’s hospice for palliative care, the health of the mother must also be considered and suitable practical and emotional support arranged as need

- **Family present at time of death**: Identify if the parents wish to be present when their baby dies and if they wish to hold their baby before or after death. Do the parents wish any other family or friends to be present

- **Timing of death**: Parents should be made aware that the time until death can vary from minutes to hours and possibly days

- **Staff present for end of life care**: The staff who will be responsible for managing this period should be identified in advance if possible

- **Transition discharge**: to home or other services for palliative care: If a transition is involved prior to a baby dying then ensure that the transition plan has been made and communicated in advance with relevant staff so the family can have optimal support

- **Organ donation**: If relevant, the parents should be informed 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. The local transplant coordinator can help establish if a transplant is feasible. United Kingdom Hospital Policy for Organ and Tissue Donation (UK, Transplant, April 2003 http://www.organdonation.nhs.uk/about_transplants/donor_care/policy_documents/uk_hospital_policy_for_donation.pdf

- **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 or during the period of supportive postnatal care

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**Care Goal: Care after death**

*Bereavement support should be provided all along the care pathway and continue through the baby’s death and beyond.*

**Standard of clinical care:**

- Review and confirm that the relevant points of the care plan are up to date
- Ensure parents aware of their choices in caring for their baby’s body
- Ensure death confirmed, death certificate completed and discussed with the family
- Parents should be given details of how to register their baby’s birth and death
- Re assess bereavement needs of the parents and siblings
- Ensure parents have been offered medical and bereavement follow up
- Baby’s death should be communicated to relevant professionals and agencies (verbally and or written within 24 hours)
- Assess the needs for staff support and debrief.

**Important points of care:**

- **Certification of death**: If a baby is born alive and subsequently dies, the birth and death of the baby need to be registered. Parents should be given both verbal and written information about how and where to register the birth and death of their baby. It is helpful to identify in advance the
doctor who will sign the death certificate. 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 procurator fiscal if the doctor has not seen the child prior to death or within 14 days of death. The care plan should indicate who and when to inform if 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 [http://www.uk-sands.org/Improving-Care/Resources-for-health-professionals/Forms-and-certificates-to-download.htm](http://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.
Ongoing Care: these goals should be delivered and reassessed throughout the care of a baby with palliative care needs

Care Goal A: Comprehensive family centred care plan

Early initiation of an initial and constant re-evaluation of a family’s bereavement, cultural, spiritual, social and psychological needs helps maintain the quality of palliative care.

Standard of clinical care:
The admission assessment (first 24 hours) should include discussion and documentation of:

- The baby’s immediate family members: parents, siblings and grandparents
- The family’s religious or spiritual needs
- The family’s diversity and cultural issues
- The family’s social needs
- The family’s psychological and bereavement needs

Reassess a family’s bereavement and psychological needs at each Goal of care

Important points of care:
An early informal discussion and documentation of a baby’s immediate family tree is helpful in maintaining family centred care.

Bereavement and psychological assessments can be supported by counsellors and psychiatrists if felt to be out with the skills of the lead professionals.

Assess the cultural, religious and or spiritual needs of the family. Discuss at all points of the care plan whether family wish for specific religious, spiritual support, rituals from hospital services or their own representative. Early assessment of a family’s social circumstances and needs is helpful if support may be required.

Care Goal B: Flexible parallel care planning

Every baby and family should have a flexible care plan, developed in partnership with them for the delivery of co-ordinated care to enhance family strengths and meet needs.

Standard of clinical care:

- A fetus or baby should have their overall needs reviewed on a regular basis by the medical team responsible for care including any changes in palliative needs
- All possible scenarios eg. Immediate death and the possibility of long term survival should be considered and planned for with the family
- Detailed discussions will need to take place regarding parallel planning in the event that the baby survives
- Consider use of CYPADM form at all Goals of care

Important points of care:
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. 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.
Care Goal C: Communication and documentation

Every family should be supported by a care process that is based on good communication between professionals across all care settings.

Standard of clinical care:
- The consultant responsible for care (or lead professional) should update parents as the care plan develops and document all discussions with parents in medical notes.
- The Consultant responsible for care should document in the medical notes and communicate outcome of discussions and agreed actions of each Goal of care. Communicate this in writing to the GP, relevant hospital staff at the local and regional units, community staff and PPS team.
- The Consultant responsible for care should agree and document the lead professionals to be communicated with at each transition stage.

Important points of care:
- **Medical documentation**: The responsibility of care may be passed between regional units, local units, community teams and the GP. Written care plans should be in plain English and all medical terms should be explained clearly so that the parents will understand them. A summary of each goal of care should be documented in the medical notes and the GP kept updated. Parents should receive copies of all the written information sent to their GP.
- **Multidisciplinary team**: Midwives, neonatal and or paediatric nurses should be included in the decision making process, care planning and communication with families.
- **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. The GP should always be included in communication updates.
- **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.
- **Timing of discussions**: Discussions and decision making may take place during the antenatal period, at birth or at any time after birth.
- **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 or paediatric clinics with families who are experiencing uncomplicated pregnancies or have children with them, or to wait somewhere with more privacy. 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.
- **Second opinion**: 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.
- **Conflict resolution**: A second internal or external opinion can help facilitate conflict resolution in the first instance.
**Care Goal D: Transition through services**

*Every family should be supported through transitions between and across services by an identified lead professional, using an integrated care process documented in a clear plan.*

**Standard of clinical care:**
- Consider whether transition to other paediatric inpatient, community services, hospice or home is a possibility and appropriate at all points of care planning
- Transition planning should begin as soon as is appropriate and possible with an assessment of parental readiness for transition
- A lead professional should be in place for the new setting of care
- Care of the mother should be considered when baby is transitioned

**Important points of care:**

*Transition*

- Discharge planning to home or community services should be a constant consideration
- A clear plan for transition should be agreed with the family, hospital, community and hospice services
- The family’s GP should be informed and included in all transition planning
- Any change in the lead professional should be identified and clearly communicated at each point of transition
- Necessary equipment and supplies for the baby and family should be provided before transfer
- Transport needs should be assessed, agreed documented and communicated with transport services
- Transport should be organised in a timely manner at home or in a hospice if the end of life period is imminent
- Relevant contact numbers of new services and professional leads should be provided to the family
- If transition to a children’s hospice is planned, a member of the hospice team should meet the family at the hospital before transition
- Care transitions should be seamless and should be supported by parallel care planning
References and consultation documents

1. A Core Care Pathway for Children with Life-limiting and Life-threatening conditions http://www.togetherforshortlives.org.uk/assets/0000/4121/TfSL_A_Core_Care_Pathway__ONLINE_.pdf


3. A Framework for Clinical Practice at the time of Birth. Arch Dis Child FNN Online October 6, 2008 as 10.1136/adc.2008.143321


8. Early years collaborative (Scottish Government). http://www.scotland.gov.uk/Topics/People/Young-People/Early-Years-and-Family/early-years-collaborative

9. Getting it right for every child (Scottish Government 2013) http://www.scotland.gov.uk/Topics/People/Young-People/gettingitright


15. MCN for children with exception health care needs: http://www.cen.scot.nhs.uk/


