



**Paediatric End of Life managed Care Network (PELiCaN)**

Guidance to support the decision making, transfer and end-of-life care of a child out with the critical care unit or ward area

*This document has been developed using adaptations from the templates for ‘Neonatal End of Life Transfer Guidance’ designed by Dr Jonathon Downie NHSGGC, the NHSGGC CHAS SCS ‘Discharge Checklist for End of Life Care’ and NHS Lothian Children’s Services Critical Care and Palliative Care Team’s ’Supporting reorientation of care outwith critical care environment [procedure]’. Thank you for granting permission to adapt these documents and for your assistance in the development of this guidance.*

NOTE

This guideline is not intended to be construed or to serve as a standard of care. Standards of care are determined on the basis of all clinical data available for an individual case and are subject to change as scientific knowledge and technology advance and patterns of care evolve. Adherence to guideline recommendations will not ensure a successful outcome in every case, nor should they be construed as including all proper methods of care or excluding other acceptable methods of care aimed at the same results. The ultimate judgement must be made by the appropriate healthcare professional(s) responsible for clinical decisions regarding a particular clinical procedure or treatment plan. This judgement should only be arrived at following discussion of the options with the patient, covering the diagnostic and treatment choices available. It is advised, however, that significant departures from the national guideline or any local guidelines derived from it should be fully documented in the patient’s case notes at the time the relevant decision is taken.

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The PELiCaN Service Development Group have endeavoured to create as complete a document as possible, however, if you have any constructive feedback or comments on this document this would be greatly appreciated. You can do this by emailing the team on nss.pelican@nhs.scot or by completing the following [feedback form](https://forms.office.com/Pages/ResponsePage.aspx?id=veDvEDCgykuAnLXmdF5JmuBVAwUjZalBu7dlhOa8DbZUM1lZU1c1VzYySE9ZOU9OWEhCU09KWjdBTCQlQCN0PWcu). **NB:** All PELiCaN documents will be subject to NSS document governance and will be subject to regular review.

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| Significant decisions about a child’s care and the diagnosis of dying are made on the basis of multi-disciplinary discussions. **It is important to be realistic regarding the timescales required for safe and effective, supported discharge.** |

# Early Identification

* Early identification of children in whom death is a potential or likely outcome.
* Facilitation of open and honest conversations with parents/carers; considering options for further treatment/interventions and also an opportunity for families to share hopes and goals in the event of this not being possible.
* Consider religious beliefs and practices and organ donation options, keep note of these.
* Consider appropriateness of a referral to the local palliative care team; remembering that palliative care should not be viewed synonymously with just end-of-life care.
* Anticipatory care plans (ACP's) can be used not only to support these conversations but also as an effective tool to record any decisions agreed between the family and the MDT.

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# Decision-making around reorientation of care

* The decision-making around reor**i**entation of care should be led by the disease specific team in conjunction with the named Critical Care Consultant (if in critical care) and also the wider MDT and the family.
* Families, children, and young people, where competent, require time to consider information and to afford opportunities for further discussion.
* Consideration needs to be given to whether a child's condition is clinically stable enough for reorientation outside of the ward or critical care unit. This process should occur early and prior to discussions about preferred place of care/death with the family.

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# Supporting decision making around preferred place of death

* In the event where transfer outwith the hospital setting is not possible, it is important that the family are aware that the team have explored all options.
* **Please note:** The services available to support care at home need careful planning in advance and services can be variable depending on location and available resources. Therefore, this option should only be offered following prior discussion with local services and the palliative care team.
* Families, children and young people should be offered a conversation around their preferred place of care/death. This discussion should include hospital [including transferring back to their local district hospital], hospice and home or other community setting where appropriate.
* **Clear conversations detailing the level of care and support that is available in all three settings is essential to enable families, children and young people to make an informed choice around reorientation outwith the hospital setting. Practitioners also need to have comprehensive and clear plans of care for each.**
* Once the plan for reorientation is confirmed and it is deemed that the child is clinically stable enough to consider transfer to community setting or back to their local hospital, a referral should be made to the local palliative care team if this has not already done. If there is no local palliative care team then advice/support can be sought from Specialist Palliative Care Teams in Scotland, and CHAS.  [***(PELiCaN Professional Information and Contacts Resource – NSD610-002.02)***](https://www.pelican.scot.nhs.uk/wp-content/uploads/2021/05/NSD610-002.02-Professional-Information-and-Contacts-Resource.pdf)

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| **Elements of care that may be delivered at home following transfer:*** + Enteral feeding including gastric and jejunal feeding
	+ Nasal or facial oxygen
	+ Enteral medications
	+ Subcutaneous delivery of symptom management medications
	+ *Respiratory support if the child was established on either home NIV or home LTV previously*
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| **Elements of care that cannot be delivered at home following transfer:*** + Ventilation
	+ Non-invasive ventilation
	+ High-flow/Vapotherm
	+ IV medications or infusions (including those which sustain life i.e. Prostin/Inotropes)
	+ IV fluids
* Blood sampling including capillary bloods and gases
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# Ensuring appropriate plans are in place to support reorientation out with the hospital setting

The required management plans to inform delivery of care are the CYPADM (Children and Young Person’s Acute Deterioration Management plan), ACP (Anticipatory Care Plan) and Symptom Management Plan. Once a decision has been made to support the reorientation of care out with the hospital setting it is important the following considerations, plans and communications occur:

## Clinical considerations

* **Resuscitation status**
	+ The child should have a clear CYPADM in place following sensitive discussion with parents and include the child or young person as appropriate.
	+ Parents should be made aware of the possibility of their child deteriorating during transfer and sensitive communication is required regarding how this will be managed.
* **Respiratory support**
	+ Inform the family of the need to discontinue ventilatory support within the first few hours on arrival at hospice or home.
	+ Consider discontinuing monitoring prior to discharge in order to support transition and encourage parents to better respond to physical changes in their child, rather than the monitors.
	+ Affirm that breathlessness and or respiratory distress will be managed with medications.
* **Feeding; Fluids and Nutrition**
	+ Enteral feeding should continue unless there is clinical indication to stop.
	+ Inform the family that IV fluids will be continued until discharge and then stopped.
	+ Discuss with the family that the focus will not be on optimal nutrition or growth but on comfort.
* **Medications**
	+ Enteral medications should be rationalised; medications which will continue to be administered at home or in the hospice should be ordered from the Pharmacy (a 7-day supply with consideration of any public holidays).
	+ A 'Just in Case' Box should be supplied prior to the transfer home or continuing care service. The Just in Case Box medications will be determined by the Symptom Management Plan for anticipated symptoms.
	+ Rationalise medications as appropriate [this should be done in conjunction with pharmacy, palliative care team/CHAS.
	+ Intravenous medications cannot be delivered at home or at the hospice; these should therefore be converted to either oral or sub-cutaneous routes. Where child in being transferred home or to the hospice, intravenous opioids and/or benzodiazepines should be converted to the sub-cutaneous route prior to the child's transfer (ideally at least 4 hours prior to transfer).
	+ Life-sustaining medications given by infusion (i.e. Prostin/Inotropes) cannot be administered at home or at the hospice. Consider if these can be stopped prior to transfer or if these should be continued until the transfer is complete, to ensure stability, and then stopped in the ambulance on arrival at, or on entry into, the destination.
	+ In addition to medications, dry stock for both enteral and parenteral medication administration will be required (see checklist) – if in doubt please contact the local palliative care team.
* **Symptom management**
	+ All children should have a Symptom Management Plan created prior to discharge. Generally, this will be led by the local palliative care team.
	+ The symptom management plan should include options for enteral medications, as well as options for a non-enteral administration if the enteral route is compromised (i.e. buccal and subcutaneous boluses).
	+ Consider any potential training needs regarding parental administration of the 'Just in Case' medications.

## Time frames

* Transfer for reorientation of care outside the hospital setting should occur within office hours i.e. Monday to Friday, 9am to 5pm (ensuring arrival at hospice or home by mid-afternoon at the latest) unless there are exceptional circumstances necessitating transfer out of hours and there is **prior** agreement from **all** teams
* Families should have clear time frames of events from arrival of ambulance team through to arrival at either the hospice or home.
	+ Families should be made aware that if life-sustaining therapies are continued for transfer i.e. ventilation/IV infusions that they will be discontinued on arrival at hospice or home, it is helpful to be specific about the timing of this i.e. immediately on arrival; after 60 minutes (this should be discussed with the transfer team and palliative care/hospice team first).
* Families often want to know how long their child will live following the withdrawal of life-sustaining therapy, it is important to answer such questions honestly but without being absolute (children often survive when we do not anticipate this and families can be distressed if expectations are different from the reality).

## Transport

* Early communication with the Scottish Ambulance Service is essential (24 hours’ notice required).
* Hospital transfer team should be identified with the skill-mix required. If the child is ventilated this will involve critical care medical/ANP staff. Ascertaining who will be available from the hospital team for transfer and the timeframe involved will help planning and communication with parents e.g. how long will the transfer team be able to be present in the hospice or home following arrival? Or the expected time of extubation following arrival.
* Clear conversations must take place with the parents around how an acute deterioration or clinical situation (e.g. accidental extubation) will be managed on transfer. In this instance, it is generally recommended that the transfer continues and basic air support (i.e. bag mask ventilation) is administered until arrival home. Parents should be sensitively counselled about this, or any other, specific plan.
* Explore with the transport team if it will be possible for a member of the family to travel with their child during the transfer.

## Palliative Care

* The palliative care team need time to ensure that appropriate community support is available; this often includes multiagency working to develop 24/7 access to medical and nursing support for families whose preference is to be at home.

## Parental wishes

* Support families to consider who they would like to be present at home or in the hospice; ensure that wider family visiting can be supported if transferring to the hospice.
* Consider any specific cultural, spiritual or religious wishes.
* Offer memory making prior to discharge; this can include hand/foot prints; family photographs (medical illustrations) etc.

# Communication and Collaboration

**Ensure an additional MDT meeting is facilitated with all MDT members in the 24 hours preceding transfer.**

* A virtual MDT should be convened 24 hours prior to transfer from hospital.
* This meeting should be chaired by the Palliative care team.
* This MDT should include:
	+ Critical care team (Medical and Nursing representation).
	+ Disease-specific teams (Medical and Nursing representation).
	+ Palliative care team (Medical and Nursing representation).
	+ Hospice team (Medical, Nursing and CHAS at Home).
	+ Community Children’s Nursing team.
	+ GP.
	+ Health Visitor.
	+ District Nurse (in some localities DN’s will support out of hours' syringe pump trouble shooting).
	+ Social Work / family support.
* The MDT should cover the following:
	+ Clinical summary of child.
	+ Clinical summary of decision making around medical interventions.
	+ Confirmation that the family are aware of the plan regarding the withdrawal of life-sustaining therapies.
	+ Brief overview of clinical management plans (see above).
	+ Confirmation that symptom management plans and medications have been arranged.
	+ Confirmation that any dry stock to support care needs have been arranged.
	+ Confirmation around feed and feeding supplies.
	+ Confirmation that CCNT/HV will continue to support ongoing needs for feed and/or equipment.
	+ Confirmation of CYPADM and plans for managing a deterioration on transfer.
	+ Highlight any specific family wishes/requests.
	+ Estimated time of arrival at home or hospice.
	+ Confirmation of what team will be present at home for the transfer team arriving with the child.
	+ Clarify clinical leadership i.e. critical care transfer team until extubation takes place then palliative care/hospice team thereafter.
	+ Ensure that the GP will support the further prescribing of medications.
	+ Ensure that the GP has updated the eKIS system regarding CYPADM and palliative nature of transfer.
	+ Identification of who will completed the death certificate. The GP may require guidance regarding the wording of the death certificate.

# Supporting ongoing care if a child survives longer than expected

* It is important that families are counselled prior to discharge that children occasionally survive longer than expected.
* Hospital follow-up for the child and family with the disease-specific team should be arranged prior to discharge as part of parallel planning.
* The palliative care or hospice team will continue to offer frequent follow-up and will liaise with disease-specific teams.
* Hospice admissions are generally for 2 weeks; if a child survives longer than this careful MDT planning is required to considered ongoing place of care i.e. hospital or home and how this can be supported.

# Post-death and Bereavement Care

* It must be identified who will lead on the immediate post-death care. This may include transfer from the home to the hospice for use of the Rainbow Room or support care at home through the use of a Flexi-mort cuddle cot.
* Ongoing bereavement follow-up should be identified and allocated to the appropriate organisation i.e. Child Bereavement UK/CHAS/or local services.
* Disease-specific teams should be encouraged to offer families follow-up as they would normally following the death of a child.

# Staff support

* Identify who will facilitate and coordinate a de-brief for staff following the death of a child.
* This de-brief will be in the format of an MDT meeting with invitations to all those involved in the child’s care.
* Signposting following this debrief to organisations for additional support if required.

Appendix One: Reorientation of care out with the Ward or Critical Care Unit Checklist

**Planning end-of-life care outside the Critical Care environment: discharge planning MDT template**

The following patient was discussed at the […………………] joint MDT on [DATE]

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| **Patient Information** |
| **First Name:** |  | **Critical Care Consultant:** |  |
| **Surname:** |  | **Disease-specific Consultant:** |  |
| **DOB:** |  | **Referral made to Palliative Care?** **Palliative Care Consultant:** | Y/N |
| **CHI:** |  | **Palliative Care Team CNS:** |  |
| **Parents/Carers:****Relationship status:** | Together / separated | **Referral made to CHAS?** **CHAS Charge Nurse:** | Y/N |
| **Community Children’s Nurse/ District Nurse:** |  |
| **Siblings:** |  | **GP:** |  |
|  |  | **Lead Clinician following transfer:** |  |
| **Clinical Summary** |
| **Diagnoses:** |  | **Current place of care:** | ***Hospital***: ***Ward***: |
| **Weight:** |  | **Feeding:** |  |
| **Medication list:** |  | **Feed:** |  |

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| **Decision Making (Consensus)** |
| **Reorientation of care:** | Y/N | **Family are aware and in agreement?****Family understand the level of support available at preferred place of care?**  | Y/NY/N |
| **Families preferred place of end of life care known?**  | Y/N | **Is this achievable?** **If no why not?** | Y/N |
| **Alternative place of end of life care:** |  |
| **Has organ and tissue donation been discussed with parents?**  | Record outcome within ACP | **Has post-mortem been discussed with parents?** | Record outcome within ACP |
| **Clinical Planning checklist to inform development of ACP**  |
| **Respiratory support:** |
|  |
| **Feeds, fluids and nutrition:** |
|  |
| **Medications:** |
| Will sub cut infusions commence pre transfer? |
| **Rationalisation of monitoring/medications:** |
|  |
| **Sustainable route for medication:** |
|  |
| **Resuscitation status CYPADM:** |
|  |
| **Other:** |
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| **Transport Planning** |
| **Transport arranged by?** |  | **Staff identified for transfer:** |  |
| **Date of transfer:** |  | **Estimated time of transfer:** |  |
| **Home access risk assessment completed?** |  | **Family travelling with team:** |  |
| **Deterioration on transfer discussed with family** | Y/N | **Plan for deterioration on transfer:** |  |
| **Care Plans** |
| **CYPADM:** | Y/N | **Symptom Management (SMP):** | Y/N |
| **ACP:** | Y/N | **Syringe driver plan (SDP):** | Y/N |
| **Disseminated by:** |  |
| **24/7 Community Support** |
| **Lead team following discharge:** |  | **Lead clinician following discharge:** |  |
| **Support: M-F 9-5pm** |  | **OOH:** | Palliative Care Team/CHAS/CCN/DN/GP/Other |
| **Nursing rota agreed:****Facilitated and coordinated by who?** | Day/Day & Night/Other | **Daily communication pathway established** |  |
| **Plan for death verification?** |  | **Plans for death certification?** |  |

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| **Palliative Care and Discharge Medications/Supplies** |
| **Discharge medications (routine and symptom mx) 7 day supply:** | Y/N | **Lock box/Just in case box arranged for control drugs:** | Y/N |
| **Feeds / NG tube / pH strips / syringes / pump/ongoing community supply arranged/ training needs:** | Y/NDetails: | **Suction machine / tubing / catheters/ ongoing community supply arranged/ training needs:**  | Y/NDetails: |
| **Oxygen / mask / tubing / humidification:** | Y/NDetails: | **Other supplies:** | Details: |
| **CME T34 Syringe Pump / batteries / lockable case:**  | Y/NDetails: | **Dry stock for syringe driver and S/C boluses:****Ongoing community supply arranged by:** | Y/N |
| **Community compatible Kardex for symptom management medications +/- syringe driver medications:**  | Y/N |
| **Family Wishes** |
| **Cultural/Religious or Spiritual:** |  | **Memory making:** |  |
| **Sibling support:** |  | **Pre-bereavement family support:** |  |
| **Post-Death Care (if known)** |
| **Options for post-death care discussed:** | **Y/N** | **Preferred place:** | Home/Hospice/Funeral director |
| **Cuddle cot or Flexmort system (if req):** |  |
| **Who will coordinate immediate and ongoing bereavement support?** |  |
| **Plan, Discussion and Outcomes: Recommendations** |
| **Follow up and parallel planning if child’s condition does not deteriorate:**  |
| **Checked at MDT by:** |  | **Date:** |  |