



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

Post Child Death Checklist Guidance

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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](mailto: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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| **Version** | **Description of amendments** | **Name & Designation** | **Date** |
| V1 | First Final Version Agreed | Shelley Heatlie | 2021 |
| V2 | Update following introduction of de-briefs guidance | Shelley Heatlie | March 2023 |
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# Introduction

This document describes a comprehensive list of procedures that should be completed after the death of a child. Attention is drawn to the  [PELiCaN – Guidance Document- Holding debriefs following the death of a baby, child or young person (NSD610-002.05)](https://www.pelican.scot.nhs.uk/guidance-documents/) the aim of which is for staff to share personal reflections of their experience as they too must process the tragic events that have unfolded in-front of them.

Throughout the guidance, ‘parents and families’ should be interpreted as anyone who holds ‘parental rights or primary responsibility’ for caring for the baby, child, or young person (B, C, Y-P). We wish to be totally inclusive, but for simplicity ‘parents and families’ is to acknowledge the relationship through the B, C, Y-P's eyes.

**Initial Support – Identify the Responsible Clinician**

One of the first administrative tasks is to identify the most appropriate responsible healthcare professional to oversee the process, usually a senior doctor who is known to the family. In many cases there may be several senior key personnel, but it is important that a single person is identified to ensure that family support transcends the death of their child; that the family continues to have a name to contact before they leave the hospital or hospice. This may be the primary disease specific Specialist, or the palliative care Consultant, a senior member of the hospice team or the family General Practitioner. Clearly identifying the responsibility of every healthcare professional in the holistic coordination of bereavement care.

One of the pivotal initial tasks is to circulate a concise but comprehensive discharge letter to all professionals known to be involved in the child’s care. The family General Practitioner is alerted to the potential of imminent family needs and may choose to initiate contact to ensure their immediate well-being. Healthcare professionals have the option to initiate contact with the family, rather than the onus being upon the family to reach out to the healthcare professional so that no-one is ‘caught-out’ by not knowing. It is the role of the responsible clinician to inform the administrative team of the death of the patient so that all future appointments are cancelled, especially where the child may be receiving care in more than one hospital or board area.

# Supporting the Family

Family members and their support network are thrown into the emotional turmoil of a profound grief reaction. Individuals progress through this journey to variable degrees at different rates and at different times. Some will be numb, in disbelief whilst others are in total despair, devastated and angry. Others may be withdrawn and crushed by sadness whilst others may want to talk, reflect and remember happier times. All emotions are compounded by difficulty in sleeping and eating.

# Siblings

Healthcare professionals must also be cognisant of the turmoil faced by any siblings who will process events differently and according to their neuro-psychological development. Siblings may not be able to ask for help. Difficulties with understanding the tragedy may arouse feelings of blame and guilt which may become manifest by a change in behaviour and personality. The profound effects of loss cannot be over exaggerated. PELiCaN recommends that families should be pro-actively offered an opportunity to meet with their deceased child’s principle care team at a time and location of their choosing. The responsibility for coordination should be that of the responsible clinician.

# Funeral Attendance

There is no national guidance regarding staff attendance at a child’s funeral. Staff may choose to attend following a direct invitation from the family, or on their own volition. Anecdotal reflection recalls the value that a bereaved family gains from seeing familiar healthcare professionals who provided the care for their child and with whom they may continue to converse throughout their bereavement.

# Post-mortem and Further Investigations/Learning

The circumstances of the death may require discussion with the procurator fiscal’s office. Healthcare professionals should enquire whether the deceased child’s family wish for a hospital post-mortem (the medical staff must be able to write a death certificate). The intra-hospital death of a ‘B, C, Y-P' will trigger a ‘Datix’ submission. Your local process for notifying death to patient records and board staff should be followed; this is also applies to deaths that occur outside the hospital (hospice or home).

**Key Suggestion:** It is important that patient records and boards staff are informed of all deaths as soon as possible. This is to ensure that future appointments or planned investigations are cancelled and avoid insensitive correspondence from the healthcare institution.

In October 2021, it became a legal requirement that all deaths of babies, children and young people up to 18 years of age are reported to the national Child Death Review hub. The referral is to facilitate a multidisciplinary and multiagency team to focus on identifying learning outcomes and process issues in an attempt to reduce the child death rate. This exploratory investigation will run parallel to any other investigation and support strategies.

# Staff wellbeing

The essential administrative tasks place additional emotional burden upon staff who may have to recount the traumatic event on multiple occasions. Staff need to be support each other and feel supported. Please look at the  [PELiCaN – Guidance Document- Holding debriefs following the death of a baby, child or young person (NSD610-002.05)](https://www.pelican.scot.nhs.uk/guidance-documents/) for more information on providing effective reflective opportunities for staff.

# Checklist

The following form is recommended as an ‘aid-memoire’, and to be completed simultaneously with the death certificate. A copy can be placed in the clinical case notes and scanned into the electronic notes for reference.

The below lists the general steps / the national process that should be completed following the death of a child. Note that steps are not linear and not all need to be followed for each child.

# Appendix 1 - Clinical Lead Checklist – Post Child Death

|  |  |  |  |
| --- | --- | --- | --- |
| **Child’s Name:** |  | **Date of Death:** |  |
| **DoB/CHI:** |  | **Place of Death:** |  |

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| **1)** | **A responsible clinician has been identified for this patient** | | | |  |
| Name: | | |  | |
| Role: | | |  | |
| **2)** | **All teams involved with caring for the child have been identified and contacted** (See list in Appendix 1 for suggested contacts) | | | |  |
| Notes: | | |  | |
| **3)** | **DATIX entry has been completed** | | | |  |
| **4)** | **Completed Serious Adverse Event Review (SAER) briefing note**  *if applicable* | | | |  |
| **5)** | **Completed referral to Procurator Fiscal (EF5 form)** *if applicable* | | | |  |
| **6)** | **Hospital post-mortem considered (medical team must write a death certificate)** *if applicable* | | | |  |
| **7)** | **Medical Certificate of Cause of Death (MCCD) Completed** | | | |  |
| Completed by: | | |  | |
| Role: | | |  | |
| **8)** | **Immediate discharge letter Completed** | | | |  |
| Completed by: | | |  | |
| Role: | | |  | |
| **9)** | **Agreement with family that following death the child’s body will be transferred to:** | | | | |
| Home (using a CuddleCot or Flexmort system) | | | |  |
| Hospice (rainbow room- prior agreement required before offer) | | | |  |
| Hospital Mortuary | | | |  |
| Funeral directors | | | |  |
| Place of Spiritual Worship (e.g. Mosque) | | | |  |
| Other: | |  | | |
| ***Key Suggestion:*** *It may be useful to look at the* [*SCYPPCN guidance for taking a child home after death*](https://www.pelican.scot.nhs.uk/guidance-documents/) *document this point.* | | | | |
| **10)** | **Offer additional memory making to parents before child goes to mortuary/home/hospice (e.g., Hand and footprints, lock of hair)** | | | |  |
| Notes: |  | | | |
| **11)** | **Agree who will contact the family in 48 hours following death to offer support** | | | |  |
| Name: | | |  | |
| Role: | | |  | |
| **12)** | **Agree who will offer the family follow up contact in the future?** *E.g., 6 weeks post-death, anniversaries, Christmas, 1-year post-death* | | | |  |
| Name: | | |  | |
| Role: | | |  | |
| **13)** | **Ensure process of arranging funeral has been discussed with family and point out extra or hidden costs** *(see* [*Funeral Costs in Scotland*](https://www.pelican.scot.nhs.uk/guidance-documents/) *document)* | | | |  |
| **14)** | **Funeral representation agreed within the team?** *If applicable* | | | |  |
| **15)** | **Arrange a ‘hot’ debrief within 72 hours if there has been a sudden or traumatic event** *If applicable* | | | |  |
| **16)** | **Arrange a holistic debrief in 4-6 weeks** *If applicable* | | | |  |
| **17)** | **Arrange Local Team Based Quality Review presentation** | | | |  |
| **18)** | **Notify child’s case to local Child Death Review team by email** | | | |  |
| **19)** | **Consider family referral to Health Board Welfare Officers** | | | |  |
| **20)** | **Close occurrence marker with police and SAS** | | | |  |
| **21)** | **Provide Family with signposting to:** | | | |  |
| * To report a death to most government organisations in one go- [‘tell us once’](https://www.gov.uk/after-a-death/organisations-you-need-to-contact-and-tell-us-once) phone line | | | |  |
| * Search for local support on [the Hub of Hope website](https://hubofhope.co.uk/) | | | |  |
| * [Cruse Bereavement Care](http://www.cruse.org.uk/) – support during loss and grief | | | |  |
| * [The Compassionate Friends](https://www.tcf.org.uk/content/ftb-siblings/) – for parents and their families; including specific support for siblings | | | |  |
| * Together for Short Lives – [When a child dies factsheet](https://www.togetherforshortlives.org.uk/get-support/supporting-you/family-resources/when-a-child-dies/) | | | |  |

# Appendix 2 - List of Possible Participants

* Allied Health Professionals – Dietician, Speech and Language Therapists, Physiotherapists, Occupational Therapist, Psychology
* Ancillary staff – Domestics, Porters, Technicians
* Community staff – General Practitioner (GP), Health Visitors, District Nurses, Paramedics, Community Childrens Nurses
* Carers- including 3rd Sector
* Chaplain or Faith Leaders
* Doctors (from any relevant specialty) at any stage in training, including Surgeons and Anaesthetists
* Education and School teams and staff
* Family Support Teams
* Nurses – Ward, Specialist, Students, Managers
* Non-clinical including Administrators, Secretaries and Ward Clerks
* Pharmacy teams
* Play teams
* Residential and respite staff- including 3rd Sector
* Social workers
* Specialist personnel – Physiologists
* Theatre staff