

Paediatric End of Life managed Care Network (PELiCaN)

Family transporting child home following death Guidance Document

Members of the PELiCaN Service Development Group have updated this document. Original document written by Scottish Children and Young People's Palliative Care Network (SCYPPCN). Thank you for your assistance in the development of this 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 or by completing the following [feedback form](#). **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	Amended from SCYPPCN doc	Shelley Heatlie Programme Manager	Feb 2025

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.

About this Guidance

This guideline is for use by professionals within paediatrics where a family wish to take their child home following their death. This could be any baby, child or young person up to the age of 18 years. The document will be reviewed in full in February 2028, if changes are not required before that time.

This guidance was originally developed by SCYPPCN in 2017, the document required updating and governance arrangements to be progressed within the Network due to the Managed Knowledge Network site being shut down. The document content was also updated given the range of PELiCaN processes now also in place to support staff.

The group updating this document consisted of staff from a range of areas including

- Nursing from NHS Grampian, CHAS and NHS Greater Glasgow and Clyde
- Bereavement Lead from NHS Lothian Children's Service

The original document was created by a wider range of staff including

- Nursing from NHS Grampian and NHS Greater Glasgow and Clyde, NHS Lanarkshire, NHS Ayrshire and Arran, NHS Dumfries and Galloway, NHS Blood and Transplant, CHAS, NHS Lothian and NHS Tayside
- Consultants from NHS Ayrshire and Arran, CHAS and NHS Greater Glasgow and Clyde
- Funeral Directors from Cooperative Funeral Directors, Glasgow
- Police Scotland
- Pathology from NHS Greater Glasgow and Clyde

The methodology used to update this guidance was

- Reviewed previous document for information that was available elsewhere, in need of updating or no longer relevant.
- Updated based on current processes in Boards
- Considered best practice as a group and agreed process by consensus.
- Adapted previous guideline
- Document sent for consultation to members of the steering group and SCYPPCN
- Document ratified by Steering Group on 12th March 2025 and SCYPPCN on 11th March 2025
- Document sent for information to NSD Senior Management Team on 7th April 2025.

Introduction

It is important for both parents and staff to be aware that in Scotland, unless a Procurator Fiscal post-mortem examination is required, there is no legal reason why a child cannot be taken home after they have died. While it will not be appropriate for every family or every clinical situation, this choice allows parents an opportunity to spend more time with their child with the support of family and friends and to say goodbye in their own environment.

When a Procurator Fiscal post-mortem examination is required, parents cannot take their child home prior to the procedure. Depending on the circumstances they may be able to have their child at home following the examination however it is essential that staff seek advice from the Mortuary and Procurator Fiscal before advising the family on this.

This guidance document will provide information to professionals supporting families who wish to take their child home after death and should be used in conjunction with local Health Board policies. This guidance may also be used when transferring to hospice or place of worship. There is a family information leaflet at the end of this guidance document which can be given to families to support this process.

Care in Hospital

Please consider the below prompts before allowing the family to transport their child to home. The list has been broken down into 3 areas of consideration.

1. Clinical considerations

- In the case of a hospital authorised post-mortem being carried out, or if the family wish to consider tissue donation, it is advisable that the child should be cared for in the hospital mortuary. This will preserve their body in an optimal state for these procedures.
- Where a family expressly wish their child to go home prior to a hospital authorised post-mortem the mortuary must be contacted for the appropriate arrangements to be made prior to transfer home. Families should be advised that this may compromise the findings of the post-mortem examination. The time at home may be limited.
- When transferring to home, to optimise support available to the family, it is advisable to only transfer children during daylight hours.

2. Establishing family wishes

- Some families may have already captured their wishes for after death care within their child's Future Care Plan (formerly Anticipatory Care Plan). Clinicians should refer to this document for advice. However, should always be mindful and supportive, should parents wish these plans to change
- A member of the team caring for a child when they die, should ensure the hospital mortuary are notified of the death.
- Follow local hospital policy/governance to release the responsibility of the body from the hospital to the next place of care. This may be known as a 'Release of Remains' form however local adaptations of the title of the form may be in place.

3. Practical steps

- Staff should advocate for the use of a Funeral Director for transfer home, to ensure the dignity of the child and family members.
- If a child is to be taken home, early contact should be made with the families chosen Funeral Director.
- Transfer arrangements and potential space and manual handling issues within the family home must be discussed with the family.
- If parents wish to take their child home, clear and sensitive advice must be given regarding care of the child who may be susceptible to leakage of body fluids which may be distressing. Minimal handling should be advised.

4. Documentation

When the family are ready to leave the hospital, it is important that the parental details, transport arrangements, post-mortem details (if applicable) and health professional communications are recorded.

Documentation required completed prior to discharge:

- Medical Certificate of Cause of Death (MCCD) – should be completed by an appropriate professional
- MCCDs are required to be scanned to the registrar as per local health board policy.
- Family transporting child home following death Checklist (Appendix 1) - file in medical notes and copy to family
- Supply parents with 'Taking your child home after their death – Parent/Legal Guardian Guide' (Appendix 2)
- Local post death checklist/documentation must be completed.
- If the child has an [occurrence marker](#) in place, a removal of marker notification should be completed as per the process.

5. Police Scotland

If a child is being transferred home in the family's or relative's car, staff member must call 101 at earliest opportunity to inform the Police

Prior to calling 101, complete **Appendix 1** with the family. This contains all the information required by Police. The completed checklist can then be given to the family to take on their journey home.

Essential information to be shared with Police:

- A brief summary of what happened to the child including date of birth and date of death
- Child's name
- Parents names
- Home address
- Car registration
- Time of expected travel from the hospital ward or hospice
- What hospital ward or hospice the family are travelling from
- Route of travel
- Identify a contact person in the hospital ward or hospice for Police to call if required
- The Police will then log this information, and an incident number will be created. This incident number **must** then be recorded on Appendix 1.

Care during transport

The section below outlines the steps that should be followed to ensure appropriate advice is given to parents regarding the safe and dignified transportation of their child to home.

- **Transfer by a Funeral Director of the family's choice should be actively encouraged by professionals.**
- Where a family expressly wishes to transfer their child in their own or a family member's car, consideration must be made regarding the dignity and safety of all involved. This should include the route from ward to car and the ability to move, handle and secure the child within the car. Wherever possible, ensure that the person driving is safe to do so. Fatigue or distress will render transportation unsafe.
- Ensure the person uplifting the child's body has been verified as the appointed person for release.
- Prior to travel, discuss access and entry route to the family home, and best place of care for the child in the home with parents.
- Use of an appropriate infant car seat, pram or moses basket. An adult should accompany the baby in the back seat, and seatbelt used to secure carry cot/moses basket.
- Ensuring the child's head is rested slightly elevated and lying centrally as opposed to on one side, will ensure any secretions are better managed (although the latter may be contradicted if culture encourages facing towards Mecca).

- The child's body should be protected from the public view through use of sensitive coverings. A baby could be transported in their own car seat for example using an insect net and appropriate covering for privacy.

Care at Home

1. To empower parents to care for their child at home

The family should be advised to consider the practical aspects of taking their child home, e.g. entry to the house, size of the home or others living in the home

- Advise family to keep their child cool at home, however, not to have windows open, especially in warm weather to minimise the risk attracting insects.
- The use of the Flexmort CuddleCot or CoverCool systems will quietly cool the child to allow the family to spend time with their child.
- Agree before the child goes home, who will return the Flexmort CuddleCot or CoverCool system back to the hospital following the child's death.
- Family should be advised that they can care and handle their child as they wish at home. This can include washing and dressing however it should be explained that over handling can increase the rate of deterioration. Following a post-mortem minimal handling is recommended.
- Parents should be sensitively informed of the expected physical changes to their child following death (i.e. colour changes, skin integrity and leakage of body fluids, odour). Each child may display these symptoms at different times. The family should be reassured that these changes are expected and may be minimised by keeping the room cool (turning heating off in room) and by use of the Flexmort CuddleCot or CoverCool system (where this is available). If parents become concerned about any changes, advise that they can contact the Funeral Director or their identified team member, directly for advice.
- Arrange for community staff to support the family at home. This may be a Health Visitor, Community Children's Nurses or General Practitioner but will vary through localities. If the child is already known to CHAS, they may also provide support to the family at home.
- The family can choose to have their child transferred into the care of the funeral director at any time, by contacting their chosen funeral director.

2. To inform parents of their legal responsibilities regarding registration of their child's death

- Parents should be reminded that it is their responsibility to register the death of their child within 8 days. Having their child at home should not delay this process.
- Consider if the family wishes to have their child buried quickly for religious or cultural reasons, if so, it may be appropriate to contact the Registrar's office regarding the current process of Advance Registration.

Appendix 1 - Family transporting child home following death.

**Complete form prior to calling 101 to ensure information is up to date.
Copy to medical record and to the family**

Child's Name:		DoB/CHI:
Date of death:		
Parent(s) names:		
Address to be taken to:		

Parent Contact telephone number:		
Name of Hospital and ward:		
Ward Contact telephone Number:		

Date and time leaving hospital:			
Car Registration Plate:			
Make:	Model:	Colour:	
Designated Driver:			
Route Home:			

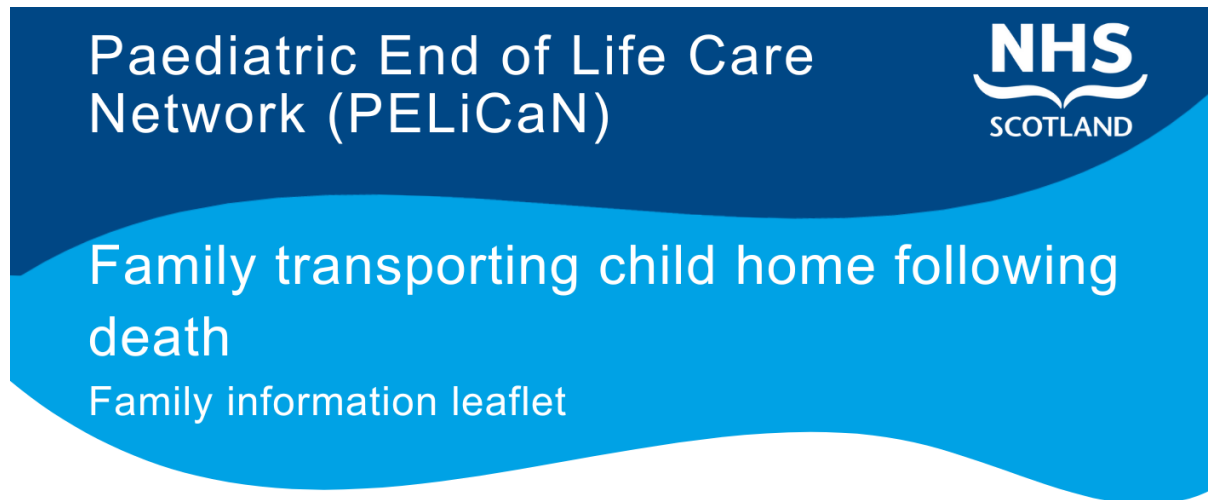
Flexmort CuddleCot or CoverCool system supplied:	Yes / No
Flexmort Information leaflet given:	Yes / No
Contact name for Flexmort equipment supply and advice:	
Contact Number:	
Person Identified to return Flexmort CuddleCot or CoverCool system:	

Police Scotland informed:	Yes / No
Who made the call to Police Scotland:	
Incident number:	

Name of staff member completing this checklist:	
Job Title:	
Signature:	

Appendix 2- Information Leaflet

A pdf of this is also available to download here - [Guidance Documents – PELiCaN](#)



This guide will refer to the term 'child' throughout but this applies to all babies, children and young people.

Taking your child home

Taking your child home after they have died will give you an opportunity to spend more time together. With the support of family and friends and to say goodbye in your own environment.

It is important you feel supported and know who to contact if you need more support or information. This guide will provide you with advice on caring for your child during this time.

Leaving the Hospital

Before leaving the hospital, you will get a 'Family transporting child home following death checklist'. This identifies:

- Your contact person once home
- Confirmation that Police Scotland are aware and a copy of the incident number, if you are using your own transport
- Your responsibility to register your child's death
- Post-mortem arrangements, if required

Safe Transportation

It is important that your child is transported in a safe and dignified manner. It is suggested that this is done by your chosen Funeral Director who will carry out this process in a dignified, caring and respectful manner. The Funeral Director will continue to provide your family with support in the coming days to help plan your child's funeral arrangements. For some children, it may be possible for you to transport them in their infant car seat or wheelchair in your own or a family member's car.



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Care at home

- It is advised that you keep your child cool at home, but not to have windows open.
- It is advised that pets are kept out of the child's room.
- The use of the Flexmort CuddleCot or the Flexmort CoverCool system will quietly cool your child to slow down the expected physical changes which happen following death. These include changes to your child's skin colour, the condition of their skin and possible leakage of body fluids or odour.
- Cooling systems may be available from your local hospital or from CHAS. This will be discussed with you before you leave the hospital or hospice and instruction on using them will be provided.
- You may wish to wash and dress your child in clothes you have chosen when they arrive home. Ideally thereafter your child should be kept in contact with the cooling system as much as possible.
- It is better not to over handle them after this, as this may increase the speed of the changes described in point three above.
- Note that minimal handling of your child is recommended if a post mortem has been carried out.
- If you transported your child home independently, we would encourage you to contact a funeral director as soon as possible. So that you can plan to have your child collected from home, when you feel the time is right professionals will guide you through this.

Legal Responsibilities

It is your responsibility to register your child's death within 8 days, taking your child home should not delay this process. You need to contact your local registration office to make an appointment to do this. The contact details of your local Register Office can be found at www.gov.uk.

Changing your mind

We recognise that circumstances and feelings change. You may decide that having your child at home may no longer feel comfortable for you as a family. If this happens, your chosen Funeral Director can provide the ongoing care of your child. The Funeral Directors will continue to allow you to visit your child and support you as a family until the funeral.

Some families may consider using Robin House Children's Hospice in Balloch or Rachel House Children's Hospice in Kinross. Both have a private Rainbow Room where your child can be cared for. Families can stay together at the hospice until the funeral allowing you to be with your child whenever you wish. Additional support for the whole family is available. Please ask your contact person for further information.



Appendix 3 – Working Group Members and Approval

Review working group		
Name	Role	Organisation
Elizabeth-Anne Cunningham	Clinical Nurse Specialist	NHS Greater Glasgow and Clyde
Jennifer Pyper	Bereavement Lead	NHS Lothian
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Original Development Group		
Name	Role	Organisation
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Aileen Crichton	Advanced Nurse Practitioner	NHS Ayrshire and Arran
Dr Jonathon Downie	Paediatrician	NHS Greater Glasgow and Clyde
Dr Paul French	Paediatric Pathologist	NHS Greater Glasgow and Clyde
Elizabeth Gillespie	Community Children's Nurse	NHS Greater Glasgow and Clyde
Neil Healy	Specialist Nurse Organ Donation	NHS Blood and Transplant
Carol Graham	Community Children's Nurse Team Lead	NHS Dumfries and Galloway
Margaret Johnston	Team Leader Integrated Community Children's Nursing Service	NHS Lanarkshire
Elizabeth-Anne Cunningham	Senior Staff Nurse	NHS Greater Glasgow and Clyde
Graeme Lannigan	Detective Chief Inspector	Police Scotland
Katrina Marshall	Senior Clinical Nurse Specialist	NHS Lothian
Dr Diana McIntosh	Consultant Oncologist	NHS Greater Glasgow and Clyde and CHAS
Fiona Reid	Diana Children's Nurse North of Scotland	CHAS
Samantha Russell	Paediatric Charge Nurse	
Jackie Stewart	Charlie House Children's Community Nurse	NHS Grampian
Joanna Taylor	Community Children's Nurse	NHS Grampian
Audrey Toshney	Complex Needs and Palliative Care Nurse Specialist	NHS Tayside

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Consultation and Approval Route	
Group	Consultation & Review
PELiCaN CSCI Taking a Child Home Development Group	Draft document circulated to group following development, minor comments received and final changes made. Document ratified.
Scottish Children and Young People's Palliative Care Network Meeting	Draft document circulated to the group, discussed at meeting where the document was ratified.
PELiCaN Steering Group	Draft document circulated to the SG, discussed at meeting where the document was ratified.