

***Collaborative guidance for staff to support families who wish to take their child home after death***

*Developed by the Scottish Children and Young People’s Palliative Care Network: Short Life Working Group*

*October 2017*

**Please note that the term ‘child’ is used throughout this guidance document and represents all babies, children and young people. The term ‘parent’ is used to represent all parents, carers and legal guardians**

This guidance has been developed by members of the Scottish Children and Young People’s Palliative Care Network (SCYPPCN). A Short Life Working Group has worked collaboratively in its production.

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SCYPPCN would also like to thank Anne Wilson, Development Officer, Children’s Health Scotland for the review of the *Taking your child home after their death: Parent/Legal Guardian* *letter* and the *Taking your child home after their death: Parent/Legal Guardian guide* in appendices two and three of this document.

This guidance will be reviewed annually by SCYPPCN.

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| Please note: There is currently a Scottish Government consultation on The Burial and Cremation (Scotland) Act 2016. This document will be updated and amended following any changes in the current legislation following this consultation. |

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**Collaborative guidance for staff to support families who wish to take their child home after death**

Introduction – Rationale for guidance

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. 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. This document will provide guidance to staff supporting families who wish to take their child home after death.

**Aims**

1. To make parents aware of the choices available to them, following their child’s death and to support their decision making.
2. To ensure that the child and their family are treated with dignity and respect.
3. To make certain that all relevant medical and nursing documentation is complete prior to transfer home.
4. To establish good communication between hospital and community services when parents decide to take their child home.
5. To ensure appropriate advice is given to parents regarding the transportation of their child.
6. To empower parents to care for their child at home.
7. To inform parents of their legal responsibilities regarding the registration of their child’s death.

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| **Staff should always refer to their own Health Board Policies on Bereavement or Sudden Unexpected Death in Childhood (SUDiC) in conjunction with this guidance.**  **Any case of SUDiC falls into the auspices of a fiscal post-mortem examination and therefore the child cannot be taken home prior to examination.** |

Care in Hospital

1. To make parents aware of the choices available to them, following their child’s death and to support their decision making

**Procurator Fiscal Cases:**

**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.**

Parental choices following the death of their child:

* Staff should provide holistic care to families during and following the death of their child wherever that may be. This would include respecting the families wishes, views and values.
* When a child dies, time should be given for all involved. No one should ever feel rushed. An experienced nurse, preferably the one that has been caring for the child and family, should co-ordinate the care and management.
* Some families may have already made decisions and plans within their child’s Anticipatory Care Plan. Refer to this document for advice however be aware that parent’s plans can change and this should be respected, as well as choices surrounding taking the child home.
* It is important to understand that having their deceased child at home is not the right choice for every family. This should be respected.
* If a child is to be taken home guidance should be sought at the earliest opportunity from the families chosen Funeral Director with regard to transfer arrangements and potential space and manual handling issues within the family home.
* In the case of a hospital authorised post-mortem, it is advisable that the child should be cared for in the hospital mortuary in order to preserve their body in an optimal state for post-mortem examination.
* If the child is suspected to have a metabolic disorder Pathology advises that children should not be taken home prior to post-mortem.
* 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 post-mortem examination, conclusions and findings. The time at home should be limited to approximately one or two days only prior to post-mortem.
* The use of a Funeral Director for such transfers should be advocated by staff to ensure the dignity of the child and family members.
* Staff should clarify where the post-mortem will be carried out. Paediatric post-mortems are currently only undertaken in Glasgow, Edinburgh and Aberdeen.
* Inform the mortuary of parent wishes for after post-mortem. Following post-mortem parents may prefer for their child’s care to continue in the mortuary or be transferred to the Funeral Director or a CHAS Rainbow Room. If parents wish to take their child home following a post-mortem, clear and sensitive advice will be required as the child will be more susceptible to leakage of body fluids from extensive examination sites which may be distressing for parents. Minimal handling should be advised.
* If the family has indicated a wish to consider tissue donation, it is advisable that the child should be cared for in the hospital mortuary in order to preserve their body in an optimal state for donation. There may be some instances where the family can take their child home for a brief time and advice should be sought from the specialist staff in tissue donation.

1. To ensure that the child and their family are treated with dignity and respect

Parents need to feel as comfortable as possible with the choice of caring for their child at home after death:

* It is important to recognise the role of the parents in caring for their child and to respect their choices at this difficult time.
* 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. They 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.
* If parents have chosen to care for their child at home following a post-mortem it is essential to inform them of the additional changes that can be expected as discussed above in Aim 1.

1. To make certain that all relevant medical and nursing documentation is complete prior to discharge home

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) – In the out of hour’s period there may be a delay in issuing the MCCD. In most circumstances this should not delay the transfer of the child to the home or hospice setting by the Funeral Director.
* Taking a deceased child home – Communication Checklist (Appendix 1) - file in medical notes
* Taking your child home after their death: Parent/Legal Guardian letter (Appendix 2) - in case they need to explain that their child has died.
* Supply parents with ‘Taking your child at home after their death – Parent/Legal Guardian Guide’ (Appendix 3)

1. To establish good communication between hospital and community services if parents decide to take their child home

Clear communication between all professionals involved is invaluable. Communications should inform the relevant professionals regarding the details of the child’s death and the arrangements that have been made in order to ensure continuity of care and ongoing appropriate support.

The following teams should be informed prior to discharge from the hospital or hospice with all communication documented clearly on the ‘Taking a deceased child home: Communication Checklist’ and filed in the child’s medical notes.

* Inform Nursing Team Leader on shift
* Attending Consultant
* Lead Professional
* CHAS (if appropriate)
* Mortuary Department
* Police Scotland (if transfer is not by Funeral Director)
* GP
* Community Nursing Team

For some families the concept of their child having to transfer via the mortuary may cause additional distress. In some circumstances this can be avoided if a dignified process is agreed in advance that meets the needs of all involved. In some centres mortuary staff feel it is advisable for the child to be transferred via the mortuary department to ensure an appropriate, private, respectful and dignified transfer for the child, their family, staff members and the public.

Where it has been agreed to bypass the mortuary department the following information must be communicated to the mortuary staff prior to transfer:

* CHI number
* Date of Birth
* Date and time of death
* Place of death (hospital and ward number)
* Address child being taken to
* Means of transport
* Name and contact number of family contact
* Arrangements made if post-mortem required and location of post- mortem authorisation form

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| **Please note: local policy should be checked as there may be some variance on procedures and documentation with mortuary departments.** |

**Police Scotland**

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

Essential information to be shared:

* 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 the Parent letter and Communication checklist.

Care during transport

1. To ensure appropriate advice is given to parents regarding the transportation of their child

* To ensure safe and dignified transportation, **transfer should be actively encouraged to be undertaken by a Funeral Director of the family’s choice**.
* 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
* Discuss access and entry route to the family home, and best place of care for the child in the home with parents, prior to travel.
* 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.
* Secretions may be better managed if the head of the child is rested slightly elevated and lying central as opposed to one side (although the latter may be contradicted if culture encourages facing towards Mecca).
* Use of body bags is not recommended for independent transfer. However the child’s body should be protected from the public through use of sensitive coverings. A baby could be transported in their own car seat using an insect net and appropriate covering for privacy.

Care at Home

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

Families 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 of flies.
* The use of the Flexmort CuddleCot or CoverCool systems will quietly cool the child to allow the family to spend time with their child.
* 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.
* 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 can also offer support to the family at home.
* Families can choose to have their child collected from the home at any time by contacting their chosen funeral director.

1. 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

Taking a deceased child home: Communication Checklist *(To be filed in medical notes upon discharge)*

Child’s name:       DoB/CHI:

Parents names:

Address taken home to:

Contact telephone number:

Name of Hospital and ward:

Date and time leaving hospital:

Post-mortem: Yes  No  Authorisation: Yes  No

Mortuary location:       Date:       Time:

Who will transfer child from home to mortuary:

Documentation given to family:

Medical Certificate of Cause of Death: Yes  No

Taking your child home after their death: Parent/Legal Guardian letter: Yes  No

Taking your child home after their death: Parent/Legal Guardian guide: Yes  No

Flexmort CuddleCot or CoverCool system supplied: Yes  No

Flexmort Information leaflet given: Yes  No

Contact name for Flexmort equipment supply and advice:

Contact Number:

Have the following people been informed:

GP: Yes  No

Health visitor: Yes  No

Community Children’s Nurse: Yes  No

CHAS or other relevant professionals involved in family’s care:

**If a funeral director is being used, there is no need to contact Police Scotland.**

Police Scotland informed: Yes  No

Who made the call to Police Scotland:

Incident number:

Name of staff member completing this letter:

Position:

Signature:

Appendix 2

Taking your child home after their death: Parent/Legal Guardian letter

Parent’s Name’s:

Name of child:

Address:

Have taken their child home after death from:

Hospital:

Address:

Telephone Number:

On (date):

**Police Scotland have been informed**

Who made the call to Police Scotland:

Incident number:

I/we the parents/legal guardians take full responsibility for our child at home, we will:

Register our child’s death

Parent(s)/Legal Guardian signatures:

Post-mortem: Yes  No

Mortuary location:       Date:       Time:

Who will transfer child to Mortuary?

**If you have any concerns, please contact:**

Name:

Contact Number:

Name of Staff member completing this letter:

Position:

Signature:

Appendix 3

Taking your child home after their death: Parent/Legal Guardian Guide

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

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

It is important that you feel supported at this time and know who to contact if you require additional 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 be given a ‘Taking your child home after their death: Parent/Legal Guardian letter’ supporting your decision to take your child home. This letter identifies:

* Your contact person once home
* Confirmation that Police Scotland are aware if you are using your own transport and have provided an incident number
* 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. We would recommend that this be undertaken 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 babies it may be possible for you to transport them in their infant car seat in your own or a family member’s car.

**Care at home**

* We advise you to keep your child cool at home, however not to have windows open.
* We would advise 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.
* CuddleCot and CuddleCool systems may be available from your local hospital or from CHAS. This will be discussed with you before you leave the hospital or hospice.
* You may wish to wash and dress you child initially at home. Over- handling after this however may increase the speed of the changes described at point 3 above. Minimal handling of your child is recommended if a post mortem has been carried out. Ideally your child should be kept in contact with the CuddleCot or CoverCool system as much as possible.
* If you transported your baby home independently we would encourage you to contact a funeral director as soon as possible so that you can make arrangements to have your child collected from home, when you feel the time is right.

**Legal Responsibilities**

It is important that you understand that it is your responsibility to register your child’s death **within 8 days** and 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](http://www.gov.uk)

**Changing your mind**

We recognise that circumstances and feelings change, and you may decide that having your child at home may no longer feel comfortable for you as a family. If this happens, the best place for the ongoing care of your child is with the Funeral Director who 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 be with your child whenever you wish. Additional support for the whole family is available. Please ask your contact person for further information.