

NHS Scotland and Children's Hospices Across Scotland (CHAS)

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

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Families who wish to take their baby 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 baby cannot be taken home after they have died. This choice allows parents an opportunity to spend more time with their baby with the support of family and friends and to say goodbye in their own environment. This document is designed to provide guidance to staff to support families who wish to take their baby home.

Aims

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

Staff should always refer to their own Health Board Policies on Bereavement in conjunction with this guidance.

Care in Hospital

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

Parental Choices following a neonatal death:

- When a Procurator Fiscal post-mortem examination is required parents cannot take their baby home prior to the procedure. Depending on the circumstances they may be able to have their baby 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.
- In the case of parental authorised post-mortem families are able to take their baby home following the procedure or depending on timings prior to the procedure by making arrangements with staff to return their baby to the hospital before leaving the Neonatal Unit (NNU), these discussions should take place in conjunction with the mortuary staff.
- It is important that we understand that taking a baby home following death, is not the right choice for every family. **This should be respected.**

2. To ensure that the baby and their family are treated with dignity and respect

Parents need to feel as comfortable as possible with the way they take their baby home after death:

- The use of the baby's name acknowledges their baby as a person and affirms them as parents.
- It is important to recognise the role of the parents in caring for their baby and to respect their choices at this difficult time.
- Parents should be sensitively informed of the expected physical changes to their baby following death (i.e. colour changes, skin integrity and leakage of body fluids, odour). They should be reassured that these changes are expected and may be minimised by the correct use of the Flexmort Cuddle Cot. If parents become concerned they can contact their Funeral Director or designated contact person documented on Parent Letter for advice (Appendix 2).
- If parents have chosen to take their baby home following a post-mortem it is important to inform them of the additional changes that can be expected (i.e. the site of suture lines and guidance on what to do if there is leakage from the site).

3. 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 our baby home: Parent Letter (Appendix 2) - in case they need to explain that their baby has died.
- Supply parents with Taking your baby home: Parent Guidance (Appendix 3)
- Supply parents with Setting up the cuddle cot at home guidance (Appendix 4)

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

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

The following teams should be informed prior to discharge from the NNU, all communication should be documented clearly on the 'Taking a baby home – Communication Checklist' and filed in the baby's case notes.

Funeral Director

We would strongly encourage families to contact a Funeral Director before leaving the NNU as they have the ability to provide 24 hour on call support once at home.

Neonatal Unit

- Inform Nursing Team Lead on shift
- Inform Senior Medical staff
- Inform Consultant Neonatologist

Hospice CHAS

- If giving Hospice contact details you must speak to Hospice nurse in charge prior to discharge so support can be agreed
- Out of hours telephone support – family details required to be logged by CHAS in the out of hours folder

Mortuary Staff

Contact Details - Tel:

Email:

Details to be communicated:

- Date of birth
- Date and time of death
- CHI number
- Ward
- Details of parents taking infant home
- Arrangement made if returning for post-mortem
- Location of medical notes and post-mortem authorisation form

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

Community Staff

- Within working hours (9am-5pm)
 - Community Midwife if < 10 days post-partum
 - Health Visitor
 - General Practitioner

Police Scotland

Call 101 at earliest opportunity to inform the Police that this is happening.

Essential information to be shared:

- A brief summary of what happened to the baby including date of birth and date of death
- Baby's name
- Parents names
- Home address
- Car registration
- Time of expected travel from the NNU (Identifying to the Police which hospital the family are travelling from)
- Identify a contact person in the Neonatal Unit for Police to call if required

The Police will then log this information and an incident number will be created. This incident number should then be recorded on the parent letter and communication checklist.

Care during Transport

5. To ensure appropriate advice is given to parents regarding the transportation of their baby

- Transport can be undertaken by the family, or via a chosen representative or their funeral director.
- It is important that a baby is transported in a safe and dignified manner, this can be achieved by:
 - Use of an appropriate infant car seat, pram or Moses basket (It is recommended that an privacy net is used to provide privacy to the baby during transportation from the hospital to the vehicle)

Care at Home

6. To empower parents to care for their baby at home

- Advise the parents to keep their baby cool at home (however not to have windows open, especially in summer, to minimise the risk of flies also highlight the risk of fresh flowers in the room)
- The use of the Flexmort Cuddle Cot will quietly cool the baby's Moses basket, crib or cot to allow parents to spend time with their baby (Appendix 4)
- Parents should be advised that they can care and handle their baby as they wish at home including bathing and dressing, however over handling may increase the rate of deterioration.
- Arrange for NNU community staff, midwife or Health Visitor to support the family when their baby is at home.
- Parents can make arrangements to have their baby collected from home, by contacting their chosen funeral directors at any time.

7. To inform parents of their legal responsibilities regarding registration

- Parents should be reminded that it is their responsibility to register the death of their baby within 8 days, taking their baby home should not delay this process. N.B Parents may also have to the register the birth at this point (check that they have been given a registration card).
- Find out if the family wishes to have their baby 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:

Communication Checklist: *(To be filed in medical notes upon discharge)*

Baby's name:	DOB/CHI:
Parents names:	
Address taken home to:	
Agreed contact telephone number:	
Time leaving unit:	

Post mortem: Yes <input type="checkbox"/> No <input type="checkbox"/>	Authorisation: Yes <input type="checkbox"/> No <input type="checkbox"/>
Date:	Time:
If yes state arrangements for returning (eg parents / funeral director):	

Documentation given to family:
Medical Certificate of Cause of Death: Yes <input type="checkbox"/> No <input type="checkbox"/>
Taking your baby home: Parent letter: Yes <input type="checkbox"/> No <input type="checkbox"/>
Taking your baby home: Parent Guidance Yes <input type="checkbox"/> No <input type="checkbox"/>

Given Flexmort Cuddle Cot: Yes <input type="checkbox"/> No <input type="checkbox"/>
Information leaflet given: Yes <input type="checkbox"/> No <input type="checkbox"/>
Returning of equipment contact number given: Yes <input type="checkbox"/> No <input type="checkbox"/>
Name of contact:

Have the following people been informed:
Community midwife: Yes <input type="checkbox"/> No <input type="checkbox"/>
Health visitor: Yes <input type="checkbox"/> No <input type="checkbox"/>
GP: Yes <input type="checkbox"/> No <input type="checkbox"/>
Hospice: Yes <input type="checkbox"/> No <input type="checkbox"/>
Any other professionals involved in family's care:
Police Scotland informed: Yes <input type="checkbox"/> No <input type="checkbox"/>
Incident number:

Appendix 2: Taking your baby home: Parent Letter

Name:
Address:

Have taken their deceased baby home from:
Hospital:
Address:

Telephone Number:
On (date):

Police Scotland informed: Yes No
Incident number:

I/we the parents take full responsibility for our baby at home, we will:
 Register our baby's death
Parent(s) signatures:

Post mortem: Yes No

Date: Time:
If yes state arrangements for returning (eg parents / funeral director):

Staff member:
Position:
Signature:
In case of concern, please contact
Name:
Contact Number:

Appendix 3:

Taking your baby home: Parent Guidance

Taking your baby home after they have died will allow you an opportunity to spend more time with your baby 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 should you require additional support or information. This guidance will provide you with advice on caring for your baby during this time.

Leaving the Hospital

Before leaving the hospital you will be given a 'Parent letter' supporting your decision to take your baby home. This letter identifies:

- Your contact Midwife/Nurse
- Confirmation that Police Scotland are aware of your decision to take your baby home (Incident Number)
- Details for returning your baby (Hospital Mortuary or Funeral Director)

Safe Transportation

It is important that your baby is transported in a safe and dignified manner. Transport can be undertaken by yourself, family member, friend by car or by your chosen funeral director. We would recommend use of an appropriate infant car seat or Moses basket secured within your vehicle.

Care at home

- We advise you to keep your baby cool at home (however not to have windows open or having fresh flowers in the room to minimise the risk of exposure to insects).
- We would also advise that pets are kept out of the baby's room.
- The use of the Flexmort Cuddle Cot will quietly cool your baby, to slow down the expected physical changes which happen following death. These include: changes to your baby's skin colour; the condition of their skin and possible leakage of body fluids or odour.
- You may care for and handle your baby as you wish at home including bathing and dressing, however over handling may increase the speed of the changes outlined above. Therefore, ideally your baby should be kept in contact with the Cuddle Cot as much as possible.
- We would encourage you to contact a funeral director as soon as possible so that you can make arrangements to have your baby 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 baby's death within 8 days, taking your baby home should not delay this process. You need to contact your local registration office to make an appointment to do this.

Changing your mind

We recognise that circumstances and feelings change, and you may decide that having your baby at home is no longer the best thing for you as a family. If this happens the best place for the ongoing care of your baby is with the funeral director and not returning to the hospital, unless your baby is having a post-mortem. Funeral directors will continue to allow you to visit your baby and support you as a family until the funeral.

Some families may consider using Rachel House Children's Hospice in Kinross or Robin House Children's Hospice in Balloch. 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 4: Setting up the Cuddlecot at home: Parent Guidance

The 'Flexmort Cuddlecot' is a cooling system which will keep your baby at the correct temperature allowing you to spend more time together at home.

Contents:

Cooling Unit
Hose with connector
Cooling mat small
Cooling mat large
Silver insulation folder
Bottle of biocide
Bottle of sterile water

How to set up the Cuddlecot:

1. Place the silver insulation foil (use double thickness) on top of the surface being used for example mattress, cot, bed or pram with the **shiny side upwards**.
2. Place the appropriate sized cooling pad on top of the silver insulation foil and check that the hose on the pad is not kinked.
3. Place a baby sheet over the pad
4. Connect the hose from the cooling pad to the second hose – you should hear a 'click'.



5. Connect the other end of the hose into the cooling unit, again you should hear a 'click'.



6. Open the water filler cap on top of the cooling unit and put a couple of drops of biocide fluid into the chamber. Open the bottle of sterile water and pour this into the chamber. Check the viewing window while doing this and fill up until almost at the top. Put the water filler cap back on the cooling unit.
7. Plug the cooling unit into an electrical socket and switch on at the plug.
Always ensure there is space around the cooling unit during its use -this allows air to circulate to prevent overheating
8. Switch the cooling unit on by pressing the ON/OFF button.
9. The cooling pad will start to fill up and the water level in the viewing window will drop. You will then have to top up the water chamber again until the level is again near the top.
Always keep the unit topped up during use. If the water level drops too low an alarm will sound and a water droplet picture will show on the unit display



10. Press the temperature button which displays ° C/°F and select '°C' and the unit will then display the current temperature of the water in the system.
11. To set the cooling unit to the desired temperature of **8°C** Press the ▼ until 8°C is displayed, then press ENTER.
12. The Unit will now begin to cool the cooling pad. This can take up to an hour to reach the set temperature.
Depending on room conditions the display will reach between 9-13°C. These are the normal operating temperatures for the unit and the pad will feel cold to touch.
13. When your baby is on the cooling mat you can dress them and cover them with a blanket / blankets
14. You can use both of the cooling matts supplied depending on the where your baby is lying for example the large matt when your baby is in the crib, mosses basket or pram and the smaller matt if baby is in your bed.

Troubleshooting

- The cooling pad will not connect to the hose
 - Press the small ball bearing situated on the hose connector- you will hear a 'click'- the connector should now work.
- The cooling pad is **NOT** cold
 - Ensure there are no kinks in the hose and that the water level is full- if not, top up the water (see step 6)
- The unit turns off after 30-60 minutes
 - The cooling system contains a timer which may have been activated. To ensure the timer is off press the timer button **until '0' is displayed.**
 - The continuous cooling set is recommended
- There is condensation on the mattress or tubing, this is not unexpected and can be resolved by wiping the condensation off and replacing the sheet over the mattress.

If you have any other issues that you cannot resolve or if you need advice

please call

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When you no longer require the Cuddlecot please call

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to arrange collection of the equipment. If you wish to dismantle the cot to put it back into the box there is a button on the underside of the cooling unit which needs to be pressed before the hose can be released.