



Taking a deceased child home (where registerable birth)

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1 Introduction and Overview

1.1 This policy has been developed to support and provide information for clinical staff regarding the process that needs to be followed to enable the smooth transfer of a deceased Infant, Child or Young Person from the Children’s Hospital, Paediatric Emergency Department, Neonatal or Maternity Unit settings directly to the family’s chosen place (referred to in this guideline as ‘home’) where requested.

1.2 For the purposed of this guidance, the term ‘child’ will be used to include all ages including infants. The term ‘infant’ is used to denote a baby up to the age of 1 year.

1.3 The policy applies:

- When the child’s death does not require referral or where a referral was not accepted by HM Coroner and the Medical Certificate of Cause of Death (MCCD) can be issued by the hospital.
- Where the birth of an infant is registerable
 - o Baby born live (any gestation).
 - o A stillbirth or termination of pregnancy at or after 24 weeks (168 days) gestation, where a baby shows no identifiable signs of life at delivery.

See **Section 5** if Hospital Post Mortem (consented PM) is being considered / arranged.

1.4 All Registerable deaths must be discussed with the Medical Examiner. The Hospital can therefore only facilitate requests to take a child home / urgent release when a Medical Examiner is available.

1.5 Medical Examiner availability is Monday to Friday 8.30am – 5pm (excluding bank holidays), by calling 259 7846 / 07960779670.

On call contact is also available until 9pm via hospital switch board.

Weekend and bank holiday contact is available 8.30am – 9pm via switchboard.

1.6 Where a death is expected out of hours, it is advisable to plan ahead and ensure discussions are held with the Medical Examiner, Specialist Bereavement Nurse / Midwife (and senior Mortuary team, where discharge would be via the mortuary) within normal working hours to facilitate the process.

2 Policy Scope –who the policy applies to

2.1 All clinical and non-clinical members of staff who are involved in the care of deceased neonates, infants, children & young people within UHL.

2.2 This policy doesn't apply to young adults who are being cared for in adult settings. In such cases please refer to;

- Last Offices Care of the Deceased UHL Policy B28/2010
- Deceased Urgent Certification and Release Outside Normal Hours UHL Policy B12/2013

3 Definitions and abbreviations

PM – Post mortem

PICU – Paediatric Intensive Care

CDOP – Child Death Overview Panel

CICU – Children's Intensive Care

MCCD – Medical Certificate of Cause of Death

NNU – Neonatal Unit

BSN - Bereavement Specialist Nurse

ATP - Anatomical Pathology Technician

CBT – Child Bereavement Team

4 Roles – who does what

4.1 The Executive Lead for this policy is the Chief Nurse

4.2 Site Duty Manager - To provide additional advice and support to the ward staff or the Local Duty Manager

4.3 Duty Managers - To oversee urgent requests to release the deceased outside Office Hours from the Childrens Hospital and Paediatric Emergency Department, and provide advice and support for complex discharges from the Maternity and Neonatal Unit as required.

4.4 All Doctors- Responsible for the effective handover of any patients nearing the end of life, with particular reference to anticipated release home.

4.5 Registered Nurses/Midwives

Responsible for confirming patient's religious and cultural needs as part of end of life care and, where anticipated release home identified

Where the request for release home has been made known prior to a death, the nurse/midwife is responsible for ensuring that the "taking your child's body home" forms (Appendix 1) is completed.

Responsible for informing the Duty Managers/Women's Manager On-call that the deceased's next of kin have requested the release home of the deceased patient, as applicable

4.6 Mortuary Staff - Anatomical Pathology Technician (APT) - To provide remote on-call advice and support to Duty Managers.

4.7 Bereavement Service Office Staff

Responsible for co-ordinating the death certification process where urgent releases of the deceased requested in Office hours

5. Policy implementation and Associated Documents

5.1 It is important to ensure that (wherever possible) the family are engaging funeral directors ideally before leaving the hospital. Where required, the Specialist Bereavement Nurse/Midwife or Senior Nurse /Midwife will assist the family in engaging with a funeral director of their choice who would be willing to support the family in the care of the child's body at home (and the option for embalming and returning the child to the home environment).

5.2 Before any decision is made, the following should have been considered and appropriately discussed by a senior member of the nursing/midwifery team and Consultant (or Registrar after discussion with a Consultant) with the family:

- The emotional impact on the whole family and particularly siblings.
- Duration of time child will be at home (where Hospital PM, this should ideally not be more than 24 hours. As part of the consent process, the family should be made aware that taking their child home may affect the ability of the Pathologist to perform or PM or interpret PM findings).
- Any significant social/safeguarding concerns for the family/wider family.
- How the family and those at home with them will manage and cope and who will be the point of contact if any problems.
- The availability and the possible option of transfer to Rainbows Children's Hospice
- Skin integrity, possible leakage and anticipated changes in the body.
- Home environment / cooling equipment availability.

5.3 Unless a Hospital PM is being arranged the family must understand that once discharged, they will be taking full responsibility for their child's body and return to the hospital will not be possible.

5.4 If a Hospital PM has been requested, the child's body cannot be released until the PM paperwork has been completed, the Mortuary has been informed / paperwork is scanned to PM

Request Mailbox and the Funeral Director has agreed to collect the child from 'home' and bring them back to the Mortuary.

A date for the Hospital PM cannot be arranged until the child is brought to the LRI Mortuary by the Funeral Directors.

PLEASE NOTE: Whilst the Hospital Pathologist understands the importance of supporting the bereavement needs of the family, they are unable to endorse this guideline where a Hospital Post Mortem is being requested and recommend constant mortuary refrigeration is maintained. As part of the conversation with families and the consent process for a Hospital Post Mortem it must be emphasised that the Pathologist reserves the right to refuse on each individual case to carry out a Post Mortem should they consider, on the return of the body to the hospital, that the lack of constant mortuary refrigeration will detrimentally affect the outcome.

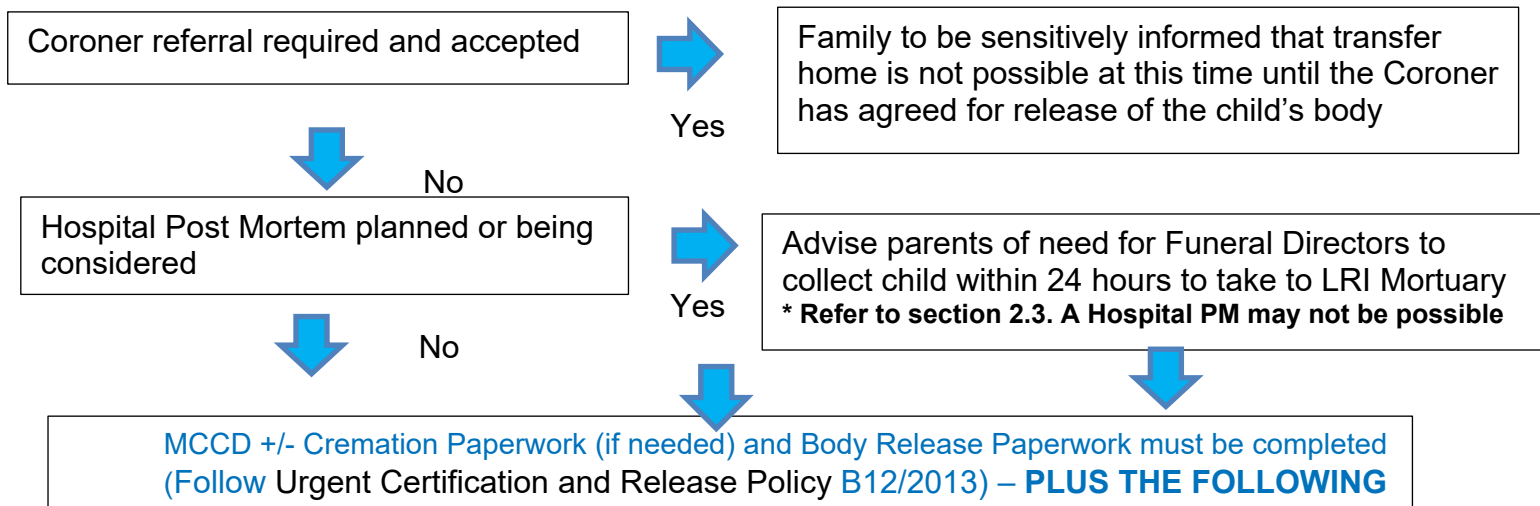
i.e., If the family chose to take their child home, a Hospital Post Mortem may not be possible.

- 5.5** The family should be provided with verbal and written details by the Senior Nurse/Midwife and Senior Doctor about how the body may change over the following hours, how to care for the body and should be advised against taking the child home if they or other family members at home feel that they may be unable to manage (appendix 2).
- 5.6** Collection by the Funeral Directors from the home should ideally be pre- arranged, with confirmation that earlier collection could also be facilitated if requested by the family.
- 5.7** It is recommended that a 'cold cuddle cot' (infants) or 'cold blanket (larger child) is used to keep the child's body cool at home. This can be loaned from the hospital (PICU/CICU/Maternity/NNU) with a local ward/unit based agreement in place for the return of the equipment to the hospital. The details of this agreement will be written on the 'Taking your child home' form (appendix 1) and ward loan form (appendix 3). The family will be shown how to use the equipment by the ward nurse/midwife before going home.

The equipment must be appropriately cleaned and checked and have an electrical safety check (by Medical Physics) on its return (completion of appendix 3).
- 5.8** The family will be provided with a 24hr contact number at the hospital to call should the family have any concerns regarding the **cooling equipment** on loan, but if once home the family feel that they are unable to manage and earlier collection of the child is needed, the family must understand that they will need to contact a Funeral Director to arrange this.
- 5.9** Where a Hospital Funeral will be arranged, the Funeral Director contracted to provide this service (presently Lee Cooper- call:01530 814999) should be contacted to agree a timeframe for transferring the child's body from their home to the LRI Mortuary and confirm 24hour access and support is available for the family should they require earlier collection
- 5.10** It should be acknowledged that although this guideline sets out a framework for this process, a flexible approach will be required to tailor the support needed by each individual family.

5.11 Children's Hospital and Emergency Department Guidance

Child Death and CDOP Process (0-18 years) UHL Childrens Hospital Guideline paperwork must be completed before release (Trust Ref: D3/2021)



5.12 Three paper copies and a scanned copy of the completed Taking your Child Home form should be made on the ward (appendix 1). This form acts as both a hospital check sheet and is essential for the family should an unforeseen situation arise where they are involved in a road traffic accident during their journey home (as instructed by the Leicestershire Police and HM Coroner). One copy is given to the parents, one is filed in the child's medical notes which are then taken to the Bereavement Services Office and one copy is taken to the Mortuary. (Out of hours take this copy to the Bereavement Services Office in an envelope addressed "for the urgent attention of the Mortuary Manager").

A scanned copy should also be emailed to the Child Bereavement mailbox and Mortuary mailbox.

5.13 'In hours' (9am -5pm Mon to Fri, excluding bank holidays) –The Nurse will seek support from a Senior/Specialist Nurse colleague as required. The Senior/Specialist Nurse will then liaise with the family, their chosen funeral director and the mortuary manager (call: 16101/ 10288) to facilitate the discharge.

Support is available where required from:

- Rainbows Paediatric Palliative Care Clinical Nurse Specialist on 07512317361
- Bereavement Support Nurse (BSN) on extension 14380 / 16776
- Ward/Unit's Bereavement Champion.

5.14 'Out of hours'

(Where the out of hours Medical Examiner has authorised the release of the MCCD)

Ward Nurse follows 3.1 to 3.3. The Duty Manager should be contacted for support with coordinating and facilitating the release. **Information relating to the discharge should be emailed to the Child bereavement mailbox** for follow up the next working day.

The Duty manager and clinical team will discuss on a case by case basis, whether it may be more appropriate for the family to delay the discharge until 'in hours' services resume (for mortuary cover and Specialist Nurse availability/support) and consider the following options:

- a- Transfer the child's body into the care of the Mortuary team or consider use of a 'cold cuddle cot' (infants) or 'cold blanket' (larger child).
- b- Continue supporting the family overnight on the ward (where bed capacity permits).
- c- Where bed capacity prevents the above, discuss the 'feasibility' with NNU/Midwifery unit managers, of transferring a deceased infant (using the Porter's body transportation trolley or covered pram as in section 3.7, for an infant) to a room with appropriate facilities within the NNU/Midwifery unit. The family would remain under the care of the discharging team.

The on-call Anatomical Pathology Technician (ATP) should be contacted via switchboard to support and coordinate discharge through the Mortuary.

5.15 Care of the body -

It is recommended that a 'cold cuddle cot' (infants) or 'cold blanket (larger child) is used to keep the child's body cool at home. This can be loaned from the hospital (PICU/CICU/Maternity/NNU) with an agreement in place for the return of the equipment to the hospital (and family is given a copy of the completed 'Taking your child home' form and equipment loan form documenting this). The family will be shown how to use the equipment by the ward nurse before going home.

The equipment must be appropriately cleaned and checked and have an electrical safety check (by Medical Physics) on its return (completion of appendix 3).

5.16 Inform GP and community teams known to the family (as per Trust Ref:D3/2021).

5.17 Transfer to mortuary- Follow guidance within the Last Offices Policy (B28/20210). It is usual practice that a child is transferred by the Porters using the covered transportation trolley to the hospital's mortuary and discharged from the mortuary.

However, for infants who die at the LRI, where preferred by the family, the child's body may be discretely transported in a covered pram which is stored and can be delivered by the Porters to the ward. In this instance the Senior Nurse who is coordinating the discharge (not the Porters) will escort the family and infant to the mortuary's family room, where a pre-arranged hand over by the nurse to the mortuary team will take place. It is the responsibility of this nurse to ensure the pram is visibly clean and returned to the Porters lodge and covered with a sheet in storage.

5.18 Discharge and Collection from the Mortuary.

- i. **Transporting an infant home (in private car or pre - arranged consenting family financed taxi):** The Senior Nurse or Duty Manger/Senior Nurse will arrange to meet the family at the rear mortuary collection door (LRI - Gate 9 Havlock Street) and assist in securing the infant into the child seat or secured Moses basket (as endorsed by HM Leicester Coroner).

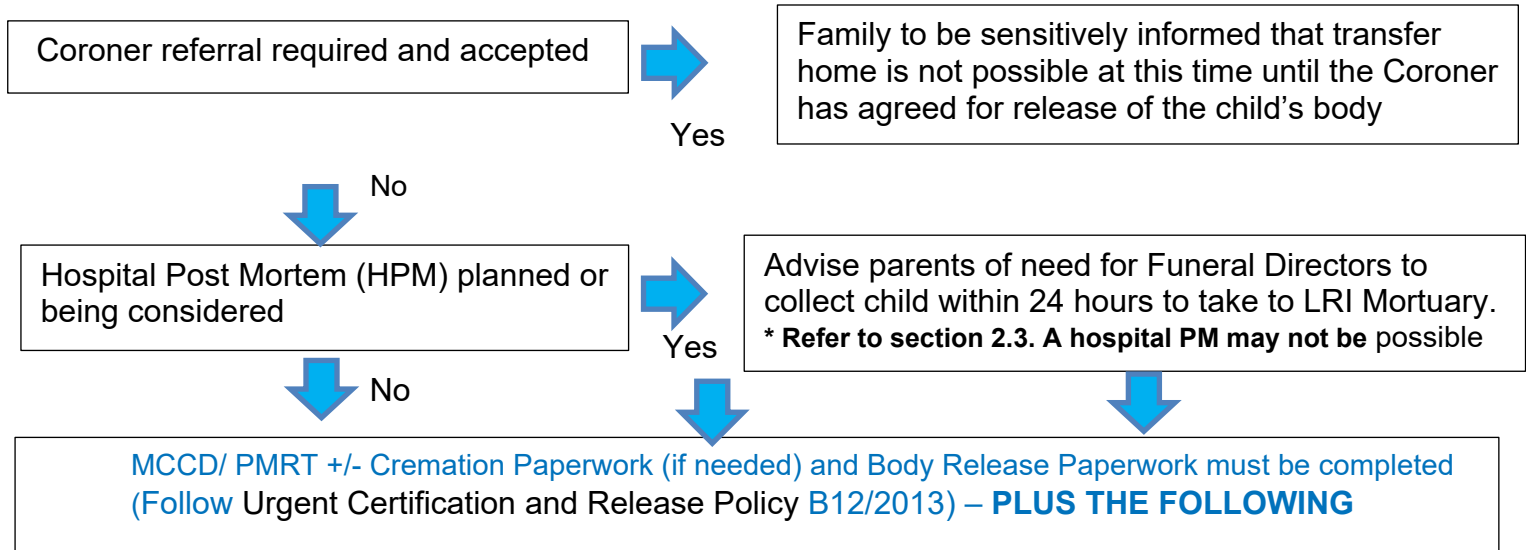
- ii. Swift Fox Taxi's may be contacted and available to offer this service: call 0116 26 28 222, although any consenting taxi company may be used.
- iii. Where transport is being arranged with the family's chosen Funeral Directors (costs may apply, please check), following the Urgent Release Policy (Trust Ref: B12/2013).
- iv. **Transporting a child home:** it is advised that for privacy and safety reasons transport should be arranged with the family's chosen Funeral Directors.

5.19 Follow up contact from the Child Bereavement Team (CBT)

The family should be informed that a member of the CBT will contact them on the next 'in hours' working day and be given contact details of how to access support if needed (See section 2.7 and appendix 1-Taking Your Child Home form).

5.20. Neonatal and Maternity Services Guidance

All relevant bereavement notification paperwork to be completed- Integrated Care Pathway



5.21 Three paper copies and a scanned copy of the completed Taking your Child Home form should be made on the ward (appendix 1). This form acts as both a hospital check sheet and is essential for the family should an unforeseen situation arise where they are involved in a road traffic accident during their journey home (as instructed by the Leicestershire Police and HM Coroner).

One copy is given to the parents, one is filed in the medical notes and one is to be taken directly to the Bereavement Services office with the MCCD (to then be given to the Mortuary team)

A scanned copy should also be emailed to the Bereavement midwives mailbox WNBereavementLink@uhl-tr.nhs.uk and the Mortuary mailbox

5.22 'In hours' (8am -4pm Mon to Fri, excluding bank holidays) – Contact the Bereavement Midwives on their mobile number 07747 475441 who can support (in collaboration with Neonatal Nursing team where applicable) in liaising with the family, their chosen funeral director and the mortuary team to facilitate the discharge.

'Out of hours' – the Midwife or Neonatal Nurse coordinating the release would only need to contact the UHL duty manager on call if the infant is to be released from the mortuary. However, In the event of the coordinator needing support, please contact the local women's manager on call via switchboard eg if there are uncertainties or process complexities in facilitating the above process (4.1 to 4.3). The Labour Ward Co-Ordinator may also be contacted for advice where required.

A discussion should be held and decision made on a case by case basis, whether it may be more appropriate for the family to delay the discharge until 'in hours' services resume (for

mortuary cover and Specialist Nurse availability/support) and the consider the following options:

- i. Transfer the child's body into the care of the Mortuary team.
- ii. Continue supporting the family overnight on the ward with use of cuddle cot (where bed capacity permits).
- iii. Where bed capacity prevents the above, discuss the 'feasibility' with NNU/Midwifery unit managers, of transferring the deceased child (using the Porter's body transportation trolley or covered pram as in section 3.7, for an infant) to a room with appropriate facilities within the NNU/Midwifery unit. The family would remain under the care of the discharging team.

5.23 Care of the body - It is recommended that a 'cold cuddle cot' is used to keep the child's body cool. This can be loaned from the hospital with an agreement in place for the return of the equipment to the hospital. (and family is given a copy of the completed 'Taking your child home' form and equipment loan form documenting this). The family will be shown how to use this before going home.

To arrange to take a Cuddle Cot home speak to the Bereavement Midwife in hours or the Labour Ward Co-Ordinator out of hours/weekends.

The equipment must be appropriately cleaned and checked and have an electrical safety check (by Medical Physics) on its returned (completion of appendix 3).

5.24 Inform GP and community teams known to the family and arrange follow up.

5.25 Infant being taken home by parents from the Ward/Neonatal Unit

Where direct discharge home from the ward/neonatal unit or bereavement suite is preferred by the family in their private vehicle or pre-arranged consenting taxi, infants may be discretely transported in a covered car 'carry seat' or pram accompanied by their Midwife/Neonatal Nurse and assistance given in securing the child seat into the vehicle or secured Moses basket (as endorsed by HM Leicester Coroner). Please contact the Bereavement Midwives if a travel basket is required. (Refer to 5.22 for appropriate in and out of hours support)

Where the baby is too small for a car seat, an appropriate 'cool transportation bag' can be used to transport their baby home.

5.26 Infant being taken home by Funeral Directors

If the child is being taken home by the Funeral Directors, this must happen via the mortuary and should follow the Urgent Release Policy.

In this instance, the parent/child separation should ideally happen on the ward and the child should be transferred to the mortuary using the covered transportation trolley.

5.27 Follow up contact and support

The family should be provided with details about the follow up post-natal and bereavement care that has been arranged by the Midwife/Nurse, tailored to the family's needs (as per the National Bereavement Care Pathway).

Details of how they can access 24 hour support if needed must be provided (see section 2.7 and appendix 1-Taking Your Child Home form). The aim is for the Bereavement Midwives to ensure that initial contact is made by themselves or by a member of the neonatal or midwifery team with the family during the 'in hours' next working day.

6 Education and Training Requirements

Awareness raising and information for staff will be provided for all clinical areas by the Bereavement Support Nurse/ Bereavement Midwife, Specialist Palliative Care Nurses and ward Bereavement Champions.

7 Process for Monitoring Compliance

Families may feedback via: Child Death Review Process, Child Bereavement Team, Maternity Bereavement Midwifery Team or Patient Information and Liaison Service.

8 Equality Impact Assessment

- 8.1 The Trust recognises the diversity of the local community it serves. Our aim therefore is to provide a safe environment free from discrimination and treat all individuals fairly with dignity and appropriately according to their needs.
- 8.2 As part of its development, this policy and its impact on equality have been reviewed and no detriment was identified.

9 Supporting References, Evidence Base and Related Policies

- Child Death and CDOP Process (0-18 years) UHL Childrens Hospital Guideline (Trust Ref: D3/2021)
- Last Offices Care of the Deceased UHL (Trust Ref: B28/20210)
- Medical Examiners UHL Policy (Trust Ref: B49/2017)
- Deceased Urgent Certification and Release Outside Normal Hours UHL Policy (Trust Ref: B12/2013)
- ReSPECT Leicester Leicestershire Rutland Policy (Trust Ref: E1/2020)
- Consent to Hospital Post Mortem Examination UHL Policy (Trust Ref B9/2010)
- Rainbows Referral: Childrens Hospital (Trust Ref C50/2021)
- LRI Emergency Department: Transport of a child to Rainbows hospice after death. 2016
- National Bereavement Care Pathway <https://nbcpathway.org.uk/nbcpathway-standards>
- UHL Bereavement Care: Stillbirth & Late Fetal Loss Integrated Pathway. June 2020
- UHL Bereavement Care: Medical Termination of Pregnancy Integrated Pathway. June 2020
- Consent to Hospital Post Mortem Examination UHL Policy B9/2010
- Stillbirth and Late Fetal Loss – Bereavement Care UHL Obstetric Guideline C275/2016

- Termination of Pregnancy in the Second and Third Trimester UHL Obstetric Guideline C30/2007
- Child Death Review: Statutory & Operational Guidance 2018 <https://www.gov.uk/>
- <https://www.verywellhealth.com/what-happens-to-my-body-right-after-i-die-1132498>
- Sands position statement Taking the baby home https://www.sands.org.uk/sites/default/files/Position%20statement%20Taking%20the%20baby%20home_2.pdf
- Information Sheet for Bereaved Families Considering Caring for their Child's Body at Home. Nottingham Children's Hospital Child Bereavement Team.
- Guidance also provided by Rainbows and Funeral Director G Seller

10. Keywords

Bereavement, Coroner, Cremation, Death, Deceased, Hospice, Mortuary, Child Bereavement Team, Bereavement Midwives, Discharge

The Trust recognises the diversity of the local community it serves. Our aim therefore is to provide a safe environment free from discrimination and treat all individuals fairly with dignity and appropriately according to their needs. As part of its development, this policy and its impact on equality have been reviewed and no detriment was identified.

Contact and review details	
<p>Guideline Lead Kim Sanger - Bereavement Support Nurse + Katie Brant Rainbows Paediatric Palliative Care Clinical Nurse Specialist</p>	<p>Executive Lead: Chief Nurse.</p>
<p>Initial working group/ meetings first discussion 22.12.21 then 24/1/22, 7.2.22, 28.2.22 4.4.22. 9.5.22 Working group - attendance or consultation Kim Sanger - Bereavement Support Nurse Katie Brant Rainbows Paediatric Palliative Care Clinical Nurse Specialist PICU/ CICU Matron Jo Wilson Maternity Bereavement Midwife Louise Robinson & Rebecca Crook Mortuary Manger Matthew Rogers Deputy Laboratory Manager Caroline Whiteley Consultant Paediatric and Perinatal Pathologist Dr Roger Malcomson, Rainbows Neonatal Palliative Care Specialist Nurse Gemma Lewis Head of Outcomes and Effectiveness Rebecca Broughton Consultant Obstetrician Penny McParland Consultant Paediatrician Dr Jeremy Tong Consultant Paediatrician Dr Claire Westrope- aware but not able to attend Consultant Neonatology Dr Robin Miralles Paediatric Palliative Care Consultant Veronica Neeffjes Advanced Neonatal Nurse Practitioner Alice Kavati Paediatric Medical Examiner- Dr Rachel Rowlands Portering Services Manager- Natalie Jeggo,</p>	<p>Medical Equipment technologist Moira Robinson and Lead Technologist Carl Bond Neonatal Unit Manager Davina Bhardwaj, CDOP Lead Dr Suzanne Armitage Diana Team Lead Julie Potts Patient partner – Roopal Shah Matt Hull – Infection Prevention Rainbows- Psychological and Bereavement Lead- David Hamilton Lorraine Taylor -Quality and Safety Midwife General Mangers Aga Archer + Sarah Mayo-Smith Tim Gray NNU equipment technologist Pauline Coser Matron NNU Steve Murray – Head of Legal Services Elaine Broughton – Head of Midwifery Presented at CHB 18/5/22, Maternity 30/5/22, NNU 7/6/22, PICU 9/6/22</p>
<p>Details of Changes made during review: New guideline</p>	

Appendix 1



University Hospitals of
Leicester NHS Trust
Leicester Royal
Infirmary

Infirmary Square
LEICESTER
LE1 5WW

Tel:0300 303 1573

Taking your child's body home

To whom it may concern

This is to confirm that the parents of (child's name).....

of (address) who died on:/...../....., at
..... :hrs., are taking their child from ward at the Maternity Unit / NNU/ Children's Hospital / Emergency
Department, to their home / other address of:.....

Child's NHS number..... Hospital number (where available).....

I / We the parent(s) hereby take full responsibility for our child whilst they are in our care and unless a Hospital Post Mortem is planned, my child cannot return to the hospital.

A translator has supported me/us in our decision making – Yes / No / Not applicable (circle as appropriate)

(Tick as appropriate):

We have made arrangements with a Funeral Director, who's name, and contact details are:

.....

Essential – Where Hospital Post Mortem (HPM) requested: We understand that a HPM may not be possible or the outcomes may be affected because mortuary refrigeration will not be maintained. A date and suitability for a HPM cannot be arranged until my child has been returned to the LRI Mortuary by the Funeral Directors which has been pre-arranged and within 24 hours (please tick or add N/A into box).

Collection date and time arranged is:

We will make our own Funeral Director or Independent Funeral arrangements at a later date.
(Funeral Director should ideally be instructed to provide ongoing support at home prior to discharge)

We will ensure that the cold cuddle cot / blanket (delete as appropriate) on loan to us is returned
(Please complete loan agreement form)

Parent(s) name(s) – Please print below

Name _____

Signature _____

Date /..... /.....

Contact number _____

Tick to confirm (required prior to release)

Coroner referral is not required (or referral declined)

Police have been informed about journey home in family car or by accepting taxi company (call 101)

GP informed (and Health Visitor / Midwife / Community care teams as appropriate)

Bereavement checklists/Integrated care pathway & certification paperwork completed. Informed family decision made.

Name of staff member completing form

Print: Nurse / Midwife Name

Role..... and Signature

Print: Senior Doctor Name (who is /has involved the Consultant)

Role..... and Signature

Further support in caring for your child at home should ideally be provided by your chosen Funeral Director, but if you do need our support, please contact the:

Bereavement Midwife (Lead for Maternity or Neonatal Unit deaths):

Call : 07747 475441 (available weekdays, excluding bank holidays 8am – 4pm)

Bereavement Support Nurse (Lead for Children’s Hospital or Emergency Department deaths).

Call: 0116258 4380 / 6776 or 07950 868337 (available weekdays, excluding bank holidays 9am – 5pm)

24 hour support contact details for family after discharge:

Funeral Director Name:

Contact number.....

24 hour support contact details for cooling equipment:

Discharging Ward – We will ensure that our team are aware that you may need to call if you have any concerns about the cooling equipment only.

If needed, call ward..... contact number:

IMPORTANT

A Bereavement Support Nurse / Rainbows Specialist Nurse / Community Midwife / Health Visitor / Bereavement Midwife / other..... (circle as appropriate) has been made aware of the discharge and a Bereavement Support Nurse / Bereavement Midwife (delete as appropriate) will be arranging for someone to contact you during the next working day to ask how you are.

1 copy of letter to be placed in child’s medical notes, 1 copy handed to mortuary team, 1 copy is given to the family.

This completed form should also be scanned and emailed to the both:

- 1- Mortuary mailbox &
- 2 - **Child bereavement mailbox** (Children’s Hospital and ED deaths) or
WNBereavementLink@uhl-tr.nhs.uk (Maternity and Neonatal deaths)

Appendix 2

Information Sheet for Bereaved Families: Caring for your Child's Body at Home.

We are very sorry that your child has died.

We acknowledge how important it may be for you and your family to have time together in a familiar place with your child. This leaflet has been written to support the information given by your ward nurse or midwife and doctor when you are considering or have decided to take your child home. It will also tell you about some of the changes you may see happening and how to care for your child.

Going home:

Before making a decision to take your child home we hope that you will have had the opportunity to consider and discuss with your doctor, nurse or midwife and family how you and those at home with you will feel able to cope and the possible alternatives of spending more time together at the hospital, arranging transfer to Rainbows Children's Hospice (if facilities are available) or visiting your child at the Funeral Directors. If there are other children at home is very important to talk to them and consider how they feel.

Your child's body should be transported in safety and with dignity and privacy. We therefore always recommend that a small child (up to the age of 1 year) is wrapped in a blanket and secured into a car seat or secured Moses basket in a car and an older child be taken home with the assistance of a funeral director.

At home:

A room and a bed area could be prepared. You may wish to arrange items such as toys, photographs or flowers around the room to make it feel special.

- To help to delay some of the natural changes that may take place in your child's body, it is important to keep your child's body cool. Radiators should be turned off and windows kept closed. Some funeral directors may loan, or you may wish to hire a portable home cooling system in warmer weather. It can also be helpful to close the curtains to prevent direct sunlight on your child's skin.

If the hospital has loaned you a cold 'cuddle cot' or 'cuddle blanket' to help to keep your child's body cool, you will have been shown how to use this and provided with contact details of how to receive support if you need it. Arrangement should also be made about returning the equipment.

It may be advisable to place a waterproof cover over the bed mattress and keep the room door closed, particularly if you have pets, to stop them entering uninvited.

You may wish to use a scented candle (with care), diffuser or an air freshener to keep the room fresh.

Changes you may notice:

It is important to know that your child's skin may alter and may become fragile. The skin will feel cold, and the colour may change with some darkening around the lips.

Reddish-purple discolouration of the skin may appear which can look like a bruise. This is caused by the pooling of blood.

The muscles in your child's body may become stiffer over time. This process is called 'rigor mortis' and it can start around the head and neck after about 3 hours from the time of death and then gradually progresses downwards to the feet and toes over the following 12 hours. Their body will relax again over the next one to three days. Due to the smaller muscle mass, this stiffening may not happen or may happen later in younger children. Please consider this when using a car seat to travel.

As your child's body starts to change, there may be some leakage of bodily fluids from different parts of the body (including the nose and ears). You may wish to gently wipe this with a damp cloth.

As body fluid levels change around the eyes, the eye lids may lift.

Sometimes the colour of the skin around the tummy may change and the tummy may swell as gases collect. You may also begin to notice changes in your child's body, which may affect the way they smell.

If you are using a cold cuddle cot or cuddle blanket, condensation may settle on the skin which will make your child's skin feel damp.

Time at home:

If your child is having a Hospital Post Mortem, arrangement will need to be made with your Funeral Director to ideally return your child to the hospital within 24 hours. It is important to understand that taking your child home will affect the Pathologists ability to report the findings of the Post Mortem.

If a Hospital Post Mortem is not required, there is no set time, but we recommend that before leaving the hospital, you consider making arrangements with the funeral director to discuss bringing your child into their care. We recommend up to 1 day at home, particularly in warmer weather, but you may choose for your child to remain at home longer. This is something you can discuss with your nurse or midwife and chosen Funeral Director.

Taking your child home form:

You will be asked to fill in this form with a doctor and nurse and keep it with you during your journey home. This is very important and if you are unexpectedly involved in a road traffic accident during your journey home you will need to show this to the Police. This form also confirms that you will be taking full responsibility for caring for your child once they leave the hospital and it will provide contact details of who you can contact if you require any support.

Appendix 3



University Hospitals of Leicester NHS Trust
Leicester Royal Infirmary
Infirmary Square
LEICESTER
LE1 5WW
Tel: 0300 303 1573

**UHL Maternity, Neonatal & Children's Hospital
Bereavement Services**

Cuddle Cot /Cooling Blanket Loan Agreement:

One copy of form given to family and one copy to remain on ward for equipment records

I (parent's name).....

Of (address)

.....

.....

have taken a cuddle cot / cool blanket, serial number on short-term loan. I have been given both written and verbal information on how to use this safely and effectively.

I understand that I should try to keep my baby in the cuddle cot / blanket for the majority of the time due to natural changes that will happen in my child's body, that I have already discussed with the bereavement midwife/ nurse and doctor.

I agree to inform the bereavement team when I no longer require the cuddle cot, when a final arrangement for collection or drop off will be made. Please call your Bereavement Midwife (Maternity/ Neonatal Unit) 07747 475441 or Support Nurse (Children's Hospital /Emergency Department) 0116 258 4380 / 6776

IT IS AGREED THAT:

- 1.0 Before the loan commences, the Hospital shall fully instruct the parent/s in the preparation and use of the equipment.

- 2.0 The parent/s will be responsible for any costs, including the cost of repairs which may arise from the failure to observe the conditions of this agreement, failure to comply with the instructions given by the Hospital on the operation, appropriate use or care of the equipment.

- 3.0 The Hospital shall (at no cost to the parent) carry out any maintenance that may be required. If the equipment fails, the Hospital will provide replacement equipment as appropriate or possible.
- 4.0 The parent shall retain possession of the equipment at all times during the period of loan and shall not allow anyone else to use it.
- 5.0 The parent shall not modify or interfere with the equipment in any way without the express agreement of the Hospital and shall notify the Hospital immediately if any defect or failures occur.
- 6.0 I am aware that in the event of any concern about this equipment, I have been given contact numbers of who to call.

I have also signed and received a copy of the 'Taking your child's body home' form: YES NO

Parental Name:	Signature:	Date:
Nurse/Midwife:	Signature:	Date:

Equipment returned to ward / unit on:

Received by: Print and sign name

Equipment checked & cleaned by:Print and sign name

Job role:

Sent to Medical Physics for electrical safety check on:

Appendix 4



University Hospitals of Leicester NHS Trust
Leicester Royal Infirmary
Infirmary Square
LEICESTER
LE1 5WW
0116 258 7565

**UHL Maternity, Neonatal & Children's Hospital
Bereavement Services**

Transportation Basket Loan Agreement:

One copy of form given to family and one copy to remain on ward for equipment records

I (parent's name).....

Of (address)

.....

.....

have taken a transportation basket number.....on short-term loan. I have been given verbal information on how to use the transportation basket for our journey home.

I understand that for safety and privacy I must keep my baby in the transport basket for the drive home.

I agree to inform the bereavement team when I no longer require the transportation basket, when a final arrangement for collection or drop off will be made.

IT IS AGREED THAT:

1. Before the loan commences, the Hospital shall fully instruct the parent/s in the reasons for the use of the equipment.

2. The parent shall be liable for and shall reimburse the Hospital for any loss or damage to the equipment, other than damage arising from or attributed to fair wear and tear.

3. The parent shall retain possession of the equipment at all times during the period of loan and shall not allow anyone else to use it.

4. The parent shall not modify or interfere with the equipment in any way without the express agreement of the Hospital and shall notify the Hospital immediately if any defect or failures occur.

5. I am aware that in the event of any concern about this equipment, I have been given contact numbers of who to call.

I have also signed and received a copy of the 'Taking your child's body home' form: YES NO

Parental Name:	Signature:	Date:
Nurse/Midwife:	Signature:	Date:

Equipment returned to ward / unit on:

Received by: Print and sign name

Equipment checked & cleaned by:Print and sign name

Job role: