



# **Guideline for Neonatal Death & End of Life Care**

<b>Contents</b>	<b>Page</b>
<a href="#"><u>Introduction</u></a>	4
<a href="#"><u>Meeting the Emotional Needs of the Family</u></a>	5
<a href="#"><u>Palliative Care Approach to Neonatal End of Life Care</u></a>	6
<a href="#"><u>Quick Guide - Summary of Medical Staff Responsibilities</u></a>	7
<a href="#"><u>Neonatal Death &amp; End of Life Care Checklist</u></a>	8-11
<a href="#"><u>Action Points from Neonatal Death &amp; End of Life Care checklist</u></a>	12-36
<b>BEFORE DEATH (if possible)</b>	
1. <a href="#"><u>Neonatal nurse allocated to family</u></a>	12
2. <a href="#"><u>Private room allocated to family</u></a>	12
3. <a href="#"><u>Consideration of Palliative Care Services</u></a>	12
4. <a href="#"><u>Consideration of Spiritual Care &amp; Bereavement Support</u></a>	12-13
5. <a href="#"><u>Memory making</u></a>	13
6. <a href="#"><u>Consideration of Neonatal Organ Donation</u></a>	13
<b>AFTER DEATH</b>	
7. <a href="#"><u>Senior members of medical staff to inform parents of death</u></a>	14
8. <a href="#"><u>Procurator Fiscal Involvement</u></a>	15
9. <a href="#"><u>Procurator Fiscal-Instructed Post Mortem</u></a>	16
10. <a href="#"><u>Parent – Authorised Post Mortem Examination</u></a>	17
11. <a href="#"><u>Mementos</u></a>	18-19
12. <a href="#"><u>Last Offices (Preparation of the baby’s body)</u></a>	20-24
13. <a href="#"><u>Taking a baby home directly from the neonatal unit</u></a>	25-26
14. <a href="#"><u>Medical Certificate of Cause of Death (MCCD) Completion</u></a>	26
15. <a href="#"><u>MCCD Review process and Advance Registration Application</u></a>	27
16. <a href="#"><u>Registration of Birth</u></a>	28
17. <a href="#"><u>Registration of Death</u></a>	29
18. <a href="#"><u>Discussion re lactation suppression/donating breastmilk</u></a>	30
19. <a href="#"><u>Inform Healthcare Team</u></a>	30-32

20. <a href="#">Funeral Arrangements</a>	33
21. <a href="#">Issue information leaflets</a>	33-34
22. <a href="#">Book of Remembrance &amp; Remembrance Tree</a>	34
23. <a href="#">Memorial Services</a>	34
24. <a href="#">Baby's belongings returned</a>	34
25. <a href="#">Recognition of a loss of a multiple pregnancy</a>	35
26. <a href="#">Follow up arrangements</a>	35
27. <a href="#">Complete documentation/Badger</a>	35
28. <a href="#">Neonatal Death Form</a>	35
29. <a href="#">Ensure appropriate reporting and review of circumstances of death</a>	36
30. <a href="#">Staff debriefing and support as appropriate</a>	36
<b><a href="#">Authors</a></b>	37
<b><a href="#">Bibliography &amp; Resources</a></b>	38
<b><a href="#">Appendix 1 - Bereavement Pack Contents</a></b>	39
<b><a href="#">Appendix 2 - NHS GG&amp;C Chaplaincy Services</a></b>	40
<b><a href="#">Appendix 3 - Procurator Fiscal Contact Details</a></b>	41
<b><a href="#">Appendix 4 - Advance Registration Application Form</a></b>	42
<b><a href="#">Appendix 5 - Taking Our Baby Home: Communication Checklist</a></b>	43
<b><a href="#">Appendix 6 - Taking Our Baby Home: Parent letter</a></b>	44
<b><a href="#">Appendix 7 - Use of the Flexmort Cold Cot Cooling system (Cuddle Cot™)</a></b>	45
<b><a href="#">Appendix 8 - Ward Release Form (Neonatal)</a></b>	46
<b><a href="#">Appendix 9 - Cold Store Facility SOP</a></b>	47-52
<b><a href="#">Appendix 10 - Repatriation to other parts of UK or elsewhere</a></b>	53
<b><a href="#">Appendix 11 - "No Procurator Fiscal Interest" Form (For Repatriation)</a></b>	54
<b><a href="#">Appendix 12 - "Freedom from Infection" Certificate (For Repatriation)</a></b>	55
<b><a href="#">Appendix 13 – Anticipatory Care Planning &amp; CYPADM Information</a></b>	56
<b><a href="#">Appendix 14 – Example Post Mortem Authorisation Form &amp; Completion Guidance</a></b>	57

## Introduction

The '**Guideline for Neonatal Death & End of Life Care**' provides staff with the relevant information and resources to facilitate the best possible care for babies and their families at the end of life and following death.

- This guideline is inclusive of all patients, family members and staff in respect of age, disability, gender, religious faith, beliefs and sexual orientation.
- This guideline is applicable to all members of staff working within NHS Greater Glasgow & Clyde who find themselves in the position of dealing with a neonatal death in the course of their work.
- This guideline aims to ensure a seamless transition of care for the family from the acute hospital setting to primary care by encouraging and facilitating effective communication.
- This guideline follows a holistic approach to dealing with neonatal loss and is intended to ensure that staff are responsive to the physical, psychological, emotional, and spiritual needs of families who are experiencing the death of a baby in the neonatal period.
- The Director of Women and Children's Services has overall corporate responsibility for the content of this document entitled "Guideline for Neonatal Death".
- Regular review and updating of this guideline will be undertaken and will take into account any changes to legislation in respect of any aspect of Neonatal Death.
- The guideline was written in accordance with the following legislation and guidance:

[Human Tissue \(Scotland\) Act 2006](#)

[Certification of Death \(Scotland\) Act 2011](#)

[The Crown Office and Procurator Fiscal Service \(2015\) Guidance](#)

[Burial & Cremation \(Scotland\) Act 2016](#)

[General Register Office for Scotland](#)

[NHS "Code of Practice on Protecting Patient Confidentiality"](#)

## Meeting the emotional needs of the family

The death of a baby is considered one of the greatest stresses parents can experience, evoking an intense grief reaction. Parents need to be affirmed in their role and sensitively supported to allow them to make the right decisions for themselves and their families.

Studies have consistently demonstrated the important role health care professionals play in supporting parents in the wake of such loss. They emphasise the importance of clear communication, honest dialogue and shared decision making.

As health care professionals, we strive to help parents through the grieving process by offering caring, professional support and providing high quality, family-focussed care. Care that is sensitive and appropriate plays a vital role in helping parents along this difficult journey of grief.

All families are unique and it is important that our advice is tailored to reflect our knowledge of the individual family, their wishes and needs. It is critical to remember that bereaved parents will remember these moments for the rest of their lives and our role can significantly impact their experience.

The [Neonatal Death & End of Life Care Checklist](#) was designed to provide practical support to staff in the provision of holistic care to families following a neonatal death. Whilst the checklist has traditionally been completed by the neonatal nurse caring for the baby and family at time of death, it is important that **all staff** familiarise themselves with this guidance. A [Quick Guide -Summary of Medical Staff Responsibilities](#) can be found on page 7 of the guideline.

All documentation required for completion of the Neonatal Death & End of Life Care Checklist is contained within a folder referred to as the [Bereavement Pack](#) (Appendix 1). These folders can be made available for use throughout all NHS Greater Glasgow & Clyde neonatal units, paediatric wards, midwifery led units and accident and emergency departments.

Remember:

- Reactions to the death of a baby can vary, even within the same family – we must respect this and adjust our approach to provide support accordingly
- Communication must always be empathetic, respectful and sensitive
- Parents should be affirmed in their role as parents and be involved in decision making
- Consider offering families [spiritual care](#) and [bereavement support](#) at an appropriate time

**Specific resources to support staff dealing with those who are bereaved can be found at [www.sad.scot.nhs.uk](http://www.sad.scot.nhs.uk) (NHS Education for Scotland, 2015)**

## Palliative Care Approach to Neonatal End of Life Care

*Palliative care for children is the active total care of the child's body, mind and spirit, and also involves giving support to the family. It begins when illness is diagnosed, and continues regardless of whether or not a child receives treatment directed at the disease. Health providers must evaluate and alleviate a child's physical, psychological, and social distress. Effective palliative care requires a broad multidisciplinary approach that includes the family and makes use of available community resources; it can be successfully implemented even if resources are limited. It can be provided in tertiary care facilities, in community health centres and even in children's homes.*

WHO Definition of Paediatric Palliative Care 1998

With continuing advancements in both antenatal and neonatal care, perinatal palliative care continues to pose significant challenges to those working in the field. The goals of neonatal medicine are to sustain life and restore health, however it is important to acknowledge that this is not always possible and as a result, professionals must strive to provide the best possible care until the end of life. Palliative care has been shown to increase quality of life, reduce invasive and expensive care at the end of life and improve the wellbeing of children and their families. [See Action Point 3](#) for further information on the local palliative care services available.

**Anticipatory Care Planning** is a focused MDT/family approach to decision making and care planning. It can help to prioritise and facilitate choices and decision making for infants and families during life and, importantly, at the end of life. Care plans should contain clear guidance for the management of clinical deterioration and should reflect the wishes the family. For more information please see [NICE Guideline NG61 'End of life care for infants, children and young people with life-limiting conditions: planning and management'](#). See [Appendix 13](#) for further information relating to ACPs and CYPADM forms.

### Reorientation of Care

In 2015 the RCPCH published its expert guidance on '[Making decisions to limit treatment in life-limiting and life-threatening conditions in children: a framework for practice](#)'. This guidance provides a detailed account on the clinical, ethical and legal aspects of reorienting care, including a framework for the rare occasions where there are disagreements between parents and healthcare professionals.

### Together for Short Lives New Perinatal Pathway for Babies with Palliative Care Needs, Second Edition 2017

In collaboration with Bliss and Child Bereavement UK, and with mutli-disciplinary input from across the country, the charity 'Together for Short Lives' has created a dedicated perinatal care pathway to guide professionals from the point of recognition that a baby may not survive for long after birth and through their neonatal period.

The link to a download request for this pathway can be accessed at [www.togetherforshortlives.org.uk/perinatalpathway](http://www.togetherforshortlives.org.uk/perinatalpathway)

### Palliative Care on Neonatal Units

Produced in 2014 by Chelsea & Westminster NHS Foundation Trust and endorsed by the RCPCH and BAPM, [Practical guidance for the management of palliative care on neonatal units](#) aims to help staff providing care to babies with life-limiting conditions.

## **Guideline for Neonatal Death & End of Life Care** **Quick Guide - Summary of Medical Staff Responsibilities**

### **BEFORE DEATH (if possible)**

- Oversee and support completion of [Neonatal Death & End of Life Care Checklist](#) by [allocated nursing staff](#). Ensure all staff involved are comfortable in their role and feel supported; consider a [‘prebrief meeting’](#) before death.
- Consider patient and family circumstances and offer [side room](#), [spiritual care support](#), possibility of [transfer to home](#) and [palliative care service](#) (CHAS) involvement if appropriate. Along with nursing staff, encourage [memory making](#). [Bereavement support](#) can be offered before death.
- Consider whether [neonatal organ donation](#) could be a possibility. Seek advice from [Specialist Nurse in Organ Donation \(SNOD\)](#) via Swtichboard and discuss with parents as appropriate.

### **AFTER DEATH**

- Verify and certify death following examination and record in neonatal notes. With the baby’s neonatal nurse present, [inform parents of the death](#).
- Consider whether case needs to be discussed with [Procurator Fiscal \(PF\)](#) and [discuss/proceed with PF and parents appropriately](#).
- The advantages and information accrued from a parent-authorized mortem are considerable. [Discuss benefits of PM with parents](#) (or re-visit if already raised prior to death). Obtain [consent](#) for PM
- If no Fiscal PM to be carried out, and ensuring baby’s identification is correct, complete and sign the [Medical Certificate of Cause of Death \(MCCD\)](#), and [corresponding ‘Record of Issue’](#). Advise parents about the [MCCD review process](#), option to apply for [Advance Registration](#) and need to register death within **8 days**.
- [Inform](#) hospital **mortuary staff**, patient’s **GP**, **mother’s obstetrician**, **referring unit consultant** and **CHAS team** if applicable. ([Action Points 19 a-e](#) on Neonatal Death & End of Life Care Checklist).
- Ensure Badger documentation/discharge letter, clinical notes and [neonatal death form](#) are completed.
- Ensure [follow up](#) appointment arranged for families +/- obstetrics consultant in 4-6 weeks via neonatal secretaries. Explain to parents that this will be offered.
- Ensure [bereavement support](#) is offered; this can be accessed at any time after bereavement.
- Ensure appropriate measures taken for the [review and reporting of circumstances of death](#) as appropriate ie **M&M Datix Form completion**, **Regional Clinical Governance Meeting Review**, **Significant Clinical Incident Review**, **RCOG ‘Each Baby Counts’ Case Reporting & MBRRACE Reporting**.
- Be kind to yourself and ensure wellbeing of your colleagues. Consider ‘hot’ +/- ‘cold’ staff [debriefs](#) as appropriate. Remember Chaplaincy and Psychology Services can be accessed for staff support.

## NHS GG&C Women & Children's Directorate Neonatal Death & End of Life Care Checklist

Name: Baby .....	Date of Death .....
Date of Birth .....	Time of Death .....
CHI Number.....	Name of Baby once Registered:- .....
Address..... ..... .....	Mother's Name..... Address..... .....
Consultant (Baby).....	Telephone Number.....
Consultant (Mother).....	Father's Name..... Address..... ..... Telephone Number .....

**Key:**

**Action Points 1-6: Before Death (if possible)**

**Action Points 7- 30: After Death**

ACTION	COMMENTS	DATE	SIG
<b>1</b>	<b><u>Neonatal Nurse allocated to family</u></b> <i>Consider a 'prebrief' meeting</i>	Yes <input type="checkbox"/>	Name:
<b>2</b>	<b><u>Private room allocated to family</u></b> <b><i>Could transfer home be an option?</i></b>	Yes <input type="checkbox"/> No <input type="checkbox"/>	Details:
<b>3</b>	<b><u>Consideration of Palliative Care Services, including Children's Hospice Association, Scotland (CHAS) involvement</u></b>	Yes <input type="checkbox"/> No <input type="checkbox"/>	Details:
<b>4</b>	<b>Consideration of Spiritual Care and Bereavement Support</b> a) <u>Chaplaincy Service</u> offered b) <u>Bereavement support</u> offered	a) Yes <input type="checkbox"/> No <input type="checkbox"/> b) Yes <input type="checkbox"/> No <input type="checkbox"/>	
<b>5</b>	<b><u>Memory making</u></b> Naming ceremony Photographs (Med Ill Bereavement photos/ Remember my baby)	Details:	
<b>6</b>	a) <b><u>Consideration of neonatal organ donation</u></b> b) Specialist Nurse in Organ Donation contacted: c) Discussion with family:	a) Yes <input type="checkbox"/> No <input type="checkbox"/> b) Yes <input type="checkbox"/> Not applicable <input type="checkbox"/> c) Details:	

7	<b><u>Senior member of medical staff to inform parents of death</u></b>	Informed by:		
8	<b><u>Procurator Fiscal Involvement</u></b> a) Case to be referred to PF? ( <a href="#">See Appendix 3 for Contact details</a> ) b) Fiscal investigation & PM to be carried out c) Parents informed	a) Yes <input type="checkbox"/> No <input type="checkbox"/> b) Yes <input type="checkbox"/> No <input type="checkbox"/> c) Yes <input type="checkbox"/> Not applicable <input type="checkbox"/> Informed by:		
9	<b><u>Procurator Fiscal-Instructed Post Mortem</u></b> Process of PM explained to parents by medical staff	Yes <input type="checkbox"/> Not applicable <input type="checkbox"/>		
10	<b><u>Parent - authorised Post Mortem</u></b> a) PM discussed with parents b) <a href="#">PM authorisation obtained</a> c) Perinatal Post Mortem Request Form or Post Mortem Request Form completed d) (Outwith QEUEH) Nursing staff to contact appropriate funeral directors once baby in mortuary to arrange transfer of baby to QEUEH mortuary ( <a href="#">See section 12</a> )	a) Yes <input type="checkbox"/> No <input type="checkbox"/> b) Yes <input type="checkbox"/> No <input type="checkbox"/> c) Yes <input type="checkbox"/> Not applicable <input type="checkbox"/> d) Yes <input type="checkbox"/> Not applicable <input type="checkbox"/>		
11	<b><u>Mementos</u></b> <i>Consider: <a href="#">is PF to be involved?</a></i> a) Memory Box issued b) Memento Authorisation c) Photographs taken d) Hand/Foot prints obtained e) Lock of hair obtained f) Blanket of love g) Cot card / Name bands	a) Yes <input type="checkbox"/> No <input type="checkbox"/> b) Yes <input type="checkbox"/> No <input type="checkbox"/> c) Yes <input type="checkbox"/> No <input type="checkbox"/> d) Yes <input type="checkbox"/> No <input type="checkbox"/> e) Yes <input type="checkbox"/> No <input type="checkbox"/> f) Yes <input type="checkbox"/> No <input type="checkbox"/> g) Yes <input type="checkbox"/> No <input type="checkbox"/>		

12	<p><a href="#">Last Offices (Preparation of the baby's body)</a>  <a href="#">Consider: is PF to be involved?</a>  a) Parents offered opportunity to assist?  b) ID checked x2 by two nurses &amp; Mortuary cards x2 completed  c) Clothes transferred with baby to the mortuary  d) List in comments section any clothes to be sent with the baby to the mortuary.  e) Outwith RHCG only - In cases where non-PF post mortem examination is required, nursing staff to contact appropriate funeral directors to arrange transfer of baby to QEUH  f) Family aware of mortuary viewing arrangements</p>	a) Yes <input type="checkbox"/> No <input type="checkbox"/> b) ID –Yes <input type="checkbox"/> Mortuary Cards –Yes <input type="checkbox"/> c) Yes <input type="checkbox"/> d) Comments: e) Yes <input type="checkbox"/> Not applicable <input type="checkbox"/> f) Yes <input type="checkbox"/>		
13	<p><a href="#">Parents taking the baby home directly from the neonatal unit</a>  a) Communications checklist completed  b) Mortuary phoned  c) Police informed  d) Ward Release form completed  e) Parental letter completed and signed  f) <a href="#">Cuddle Cot™</a> given to family</p>	a) Yes <input type="checkbox"/> b) Yes <input type="checkbox"/> c) Yes <input type="checkbox"/> d) Yes <input type="checkbox"/> e) Yes <input type="checkbox"/> f) Yes <input type="checkbox"/> No <input type="checkbox"/>		
14	<p><a href="#">Medical Certificate of Cause of Death (MCCD) Completed</a> (Ensure name is same as on Birth Certificate and corresponding 'Record of Issue' completed)</p>	Yes <input type="checkbox"/> Completed By: No (Pathologist MCCD) <input type="checkbox"/>		
15	<p><a href="#">MCCD review process and option of Advance Registration explained to the parents</a></p>	Yes <input type="checkbox"/> Explained By:		
16	<p><a href="#">Registration of Birth:</a>  a) Information given  b) Birth Registration Card issued?</p>	a) Yes <input type="checkbox"/> b) Yes <input type="checkbox"/>		
17	<p><a href="#">Registration of Death:</a>  a) Information given  b) Death Registration card issued?  <b>Ensure name is same as on Birth Certificate</b>  c) Parents aware to make appointment at Registry Office and that they must register the death within 8 days?</p>	a) Yes <input type="checkbox"/> b) Yes <input type="checkbox"/> c) Yes <input type="checkbox"/>		
18	<p><a href="#">Discussion re lactation suppression, avoiding mastitis, option of donor milk bank</a></p>	Yes <input type="checkbox"/> Not applicable <input type="checkbox"/>		

19	<p><a href="#">Inform Healthcare Team</a>  <a href="#">a – e Medical Staff responsibility</a>  <a href="#">f – o Nursing Staff responsibility</a></p> <p>a) Mortuary Department  b) GP</p> <p>c) Obstetric Consultant  d) Referring Unit (if applicable)  e) CHAS (if applicable)</p> <p>f) Post natal ward staff/  Community Midwife  g) Health Visitor  h) Ronald McDonald House (RHCG site only)  i) Clinical Psychology  j) Audiology  k) Newborn Screening  l) Medical Records Staff  m) Child Health  n) Bounty Company  o) Offering Baby Box Cancellation</p>	<p>a) Yes <input type="checkbox"/>  b) Yes <input type="checkbox"/> Name of NHS 24 Call Handler if applicable -  c) Yes <input type="checkbox"/>  d) Yes <input type="checkbox"/> Not applicable <input type="checkbox"/>  e) Yes <input type="checkbox"/> Not applicable <input type="checkbox"/>  f) Yes <input type="checkbox"/>  g) Yes <input type="checkbox"/>  h) Yes <input type="checkbox"/> Not applicable <input type="checkbox"/>  i) Yes <input type="checkbox"/>  j) Yes <input type="checkbox"/>  k) Yes <input type="checkbox"/>  l) Yes <input type="checkbox"/>  m) Yes <input type="checkbox"/>  n) Yes <input type="checkbox"/>  o) Yes <input type="checkbox"/></p>		
20	<a href="#">Funeral arrangements</a>	Information given: Yes <input type="checkbox"/>		
21	<a href="#">Issue Information Leaflets</a>	Yes <input type="checkbox"/>		
22	<a href="#">Book of Remembrance &amp; Remembrance Tree</a>	Information given: Yes <input type="checkbox"/> No <input type="checkbox"/>		
23	<a href="#">Memorial Services</a>	Information Leaflet: Yes <input type="checkbox"/> No <input type="checkbox"/>		
24	<a href="#">Baby's belongings returned</a>	Yes <input type="checkbox"/>		
25	<a href="#">Recognition of the loss of a multiple pregnancy</a>	Discussed with family if applicable: Yes <input type="checkbox"/> No <input type="checkbox"/> Butterfly stickers used for surviving sibling(s): Yes <input type="checkbox"/> No <input type="checkbox"/>		
26	<a href="#">Follow up arranged</a> <i>Contact details correct?</i>	Yes <input type="checkbox"/>		
27	<a href="#">Complete documentation – paperwork and Badger</a>	Yes <input type="checkbox"/>		
28	<a href="#">Neonatal Death Form Completed</a>	Yes <input type="checkbox"/> By:		
29	<p><a href="#">Ensure appropriate reporting and review of circumstances of death</a></p> <ul style="list-style-type: none"> <li>- M&amp;M datix form complete</li> <li>- Clinical Governance Meeting Review</li> <li>- Significant Clinical Incident Review</li> <li>- RCOG 'Each Baby Counts'</li> <li>- <a href="#">MBRRACE</a> Reporting</li> </ul>	<p>Yes <input type="checkbox"/>  Yes <input type="checkbox"/></p> <p>Yes/No</p> <p>Yes <input type="checkbox"/>  Yes <input type="checkbox"/></p>		
30	<a href="#">Consider Staff debrief &amp; support as appropriate</a>	Details:		

*Please return this form to the Baby's Case Notes when completed*

## Action Points from Neonatal Death & End of Life Care Checklist

### **BEFORE DEATH (if possible)**

#### **1. Neonatal Nurse allocated to Family**

A named neonatal nurse should be allocated to attend to the baby and parents' needs. If possible, this should be a nurse who knows the family. He or she should find out as much about the family as possible before meeting them. ***This nurse is responsible for completion of the [Neonatal Death & End of Life Care Checklist](#).*** It is important that all staff involved should feel supported. A 'prebrief' staff meeting before death could be considered as this is often the time staff feel is most distressing.

**2. Private room allocated to the family.** A private room should be allocated to enable privacy for the immediate and extended family. If appropriate, the family may wish to take their dying baby home and this should be facilitated if possible. See [Action point 3](#) below.

#### **3. Consideration of Palliative Care Services Involvement**

Increasingly within the neonatal service, Palliative Care services such as the Children's Hospice Association Scotland (CHAS) are involved in supporting neonatal end of life care. As well as the possibility of transfer of babies to Robin House Hospice for on-going care, if appropriate, it may be possible for a baby to be transferred home to spend their final hours or days there. In these cases, CHAS can potentially offer home nursing care support for the family. A referral to CHAS can be made via Dr Diana McIntosh (Paediatrician with an interest in paediatric palliative care based at RHCG) or directly to Robin House. CHAS may also be able to offer use of their 'Rainbow Room' which can enable parents to spend extended time with their baby after death in a non-clinical setting. For more information visit the CHAS website on <http://www.chas.org.uk>

Depending on availability, the SCOTSTAR Neonatal Transport team may be able to help facilitate transfer of a baby to hospice or home for compassionate extubation. To allow the transport service to facilitate such a move without compromising acute clinical transport services to the region, or risking having to abandon transfer, notice of **at least 24 hours** is requested to allow staffing to be allocated to such a move. Contact the West Neonatal Transport Team Office on **0141 810 6672**.

#### **4. Consideration of Spiritual Care and Bereavement Support**

##### **Spiritual Care**

Every person has spiritual needs whether they consider themselves to be religious or not. If in doubt about the customs and practices of a particular faith group, ask the family- it is better to ask than to offend.

Healthcare Chaplains are available for people of all faiths or none. The spiritual care they give is person-centred and makes no judgements about beliefs or lifestyle. Many parents may not appreciate what a chaplain does so offering their services needs to be done carefully. A [Chaplaincy Services leaflet](#) can be given to parents.

The NHSGG&C Chaplaincy Service is available to all wards and units at all times; a visit from a particular faith belief representative can be facilitated.

To contact the chaplain, ask main Switchboard to radiopage the Healthcare Chaplain for the hospital. A Roman Catholic Priest is also available at all times through main switchboard and an Imam can be contacted via the Chaplaincy Service.

The [NHS GG&C Faith and Belief Communities Manual and Chaplaincy pages on Staffnet](#) can be accessed for further information on how to support families. See [Appendix 2](#) for more information and chaplaincy contact details.

## **Bereavement Support**

As of June 2017, a bereavement support service funded by the Glasgow Children's Hospital Charity and provided by Child Bereavement UK is available to families within NHS GG&C before or after bereavement. Families can self-refer or be referred by staff, with permission. Contact Kristin O'Neill on 07795195368 or email [GHsupport@childbereavementUK.org](mailto:GHsupport@childbereavementUK.org).

## **5. Memory Making**

Parents and families should be offered the opportunity to make memories with their baby, if possible before death. This can include photograph taking, the making of hand and footprints and obtaining a lock of hair. At the QEUH and PRM sites, [Medical Illustration](#) can be contacted during office hours to take bereavement photographs.. 'Remember My Baby' is a charity which offers parents the opportunity to have volunteer professional photographers take sensitive photographs of their babies before or shortly after death. <http://www.remembermybaby.org.uk> The [Chaplaincy service](#) can also facilitate an appropriate naming ceremony, blessing or christening service according to the family's wishes.

## **6. Consideration of Neonatal Organ Donation**

Neonates >36 weeks gestation can be considered for organ and tissue donation following circulatory death (DCD). Since 2015 it has been possible to diagnose death by neurological criteria in babies > 37 weeks gestation,<sup>1</sup> which makes donation following Brain Death (DBD) also possible.

It is important that donation is considered at an early stage of end of life care planning and early discussion with the hospital Specialist Nurse in Organ Donation (SNOD) is encouraged. It is accepted practice for this discussion to take place before raising it with the family.

There are few contraindications to organ donation; therefore clinicians are encouraged to discuss all cases with the SNODs.

<p><b>SNOD in hours: 0300 123 9209</b> <b>SNOD OOH: 07659 594979</b></p>
--

Following the death of a child, many parents and families take a great deal of comfort from knowing that through donating their child's organs or tissue, other people's lives were saved or enhanced. It may be the case that it is the only positive outcome of an otherwise tragic situation.

Scottish Government guidance on neonatal organ and tissue donation will be available on their website by winter 2017. Further information is also available at <http://www.odt.nhs.uk/donation/deceased-donation/paediatric-organ-donation/donation-in-infants-and-neonates/>

<sup>1</sup><http://www.rcpch.ac.uk/improving-child-health/clinical-guidelines-and-standards/published-rcpch/death-neurological-criteria>

## **AFTER DEATH**

### **7. Senior member of medical staff to inform parents of the death.**

Medical staff are responsible for certifying the baby's death. Parents should be informed of the death as soon as possible in a sensitive and compassionate way, ideally by a senior member of medical staff known to them. The neonatal nurse should also be present at this time.

The baby should be referred to by their name. If the baby has not yet been named, the parents should be asked what they intend to call their baby.

Where possible, parents should be offered private time with their baby. If the case is to be referred to the Procurator Fiscal, please check with the Procurator Fiscal if there are any restrictions for the individual case in question. (See [Action Point 8](#)). Remember that some parents may not wish to spend time with their baby. This does not mean they don't care or love their baby, rather that it may simply be their way of coping.

- Take parents to a "Quiet Room", ensuring that there is an engaged sign posted on the door to prevent interruptions.
- Always be mindful of the parents' wishes. Do not assume that the parents wish to cuddle their baby when their baby is dying or following the death. Always ask the parents if they wish to see or hold their baby.
- Encourage parents to involve siblings and other family members as they wish.
- Do not rush parents. Afford them as much time as they need.
- Always be on hand for the parents but also offer them time alone.
- Remember, with the exception of babies requiring a *Procurator Fiscal* post mortem examination, it should also be possible for the parents [to take their baby home](#) directly from the neonatal unit, *even if a parent-authorized post mortem examination is planned.*

If parents do not want to see or hold their baby, this must be respected. It is important however to make them aware that if they change their minds they can still visit their baby later by arrangement with nursing staff, the mortuary or the undertaker depending on time lines. ([See Guidance on viewing the baby after death - Action Point 12](#)) If parents wish to have their baby with them in the neonatal unit for several hours, use of a [Cuddle Cot™](#) can be facilitated. Staff can also suggest that the parents moisturise the baby's skin with baby lotion to prevent the skin from drying out.

It may also be possible to arrange for the family to be transferred to the Rainbow Room at Robin House after the baby has died, to enable uninterrupted family time for a longer period of time, ([See Action Point 3](#)), or for the family to [take their baby home](#) directly from the neonatal unit.

## 8. Procurator Fiscal Involvement

A complete guide for reporting deaths to the Procurator Fiscal (PF) including a list of all deaths to be reported to the PF; contact details for all the Scottish Fatalities Investigation Units (SFIUs); and guidance about information required by the PF is contained within the following document:

*'Reporting Deaths to the Procurator Fiscal - Information and Guidance for Medical Practitioners'* – Produced by the Crown Office and Procurator Fiscal Service 2015', available via <http://www.crownoffice.gov.uk/publications/deaths>

### **General Points from the above document:**

- The doctor with the most detailed knowledge of the circumstances of the death should make the report to the PF.
- All reportable deaths must be notified to the PF as soon as possible after occurrence and **BEFORE** any steps are taken to issue a death certificate. If a death certificate has already been issued to a family and the PF declines to accept the cause of death, this will have to be retrieved from the family, a hugely distressing process.
- a) In normal circumstances, death reports should be made to the PF **during office hours**. In situations of urgency, particularly where the death is suspicious or there are religious rites which require to be observed, a death report may be made outside of office hours, to the on call service, contactable through the police. This facility should be used in **exceptional circumstances** only where the matter cannot wait until the next working day.
- b) The reporting doctor should provide the PF with all of the information required on the 'Notification of Death' form – (*See Appendix 3 of the above document*).
- c) Remember that the Procurator Fiscal is not medically qualified and therefore may contact their local forensic pathology team for advice regarding certification issues.

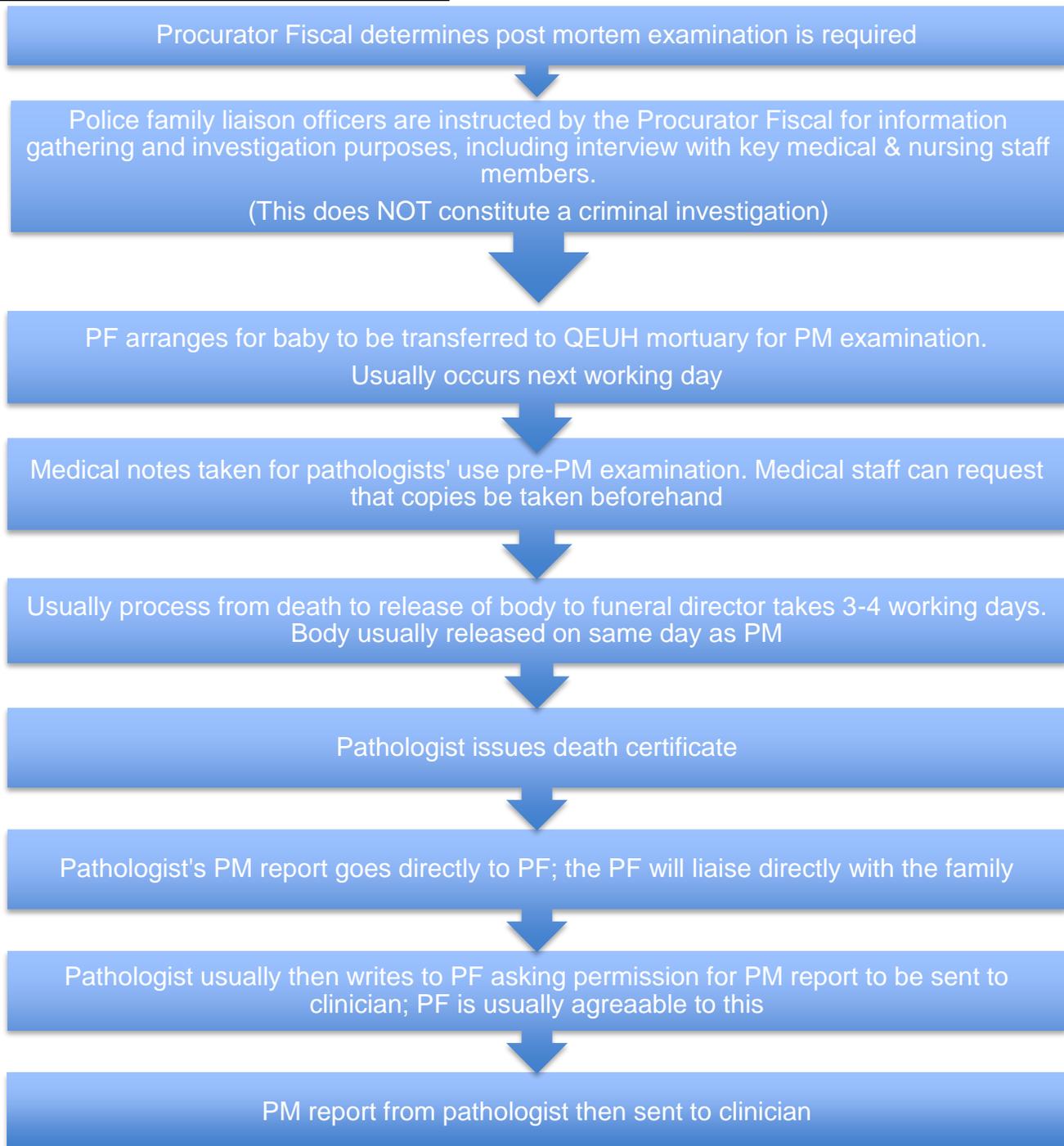
If the Procurator Fiscal is to be involved, please see PF-related information in the '[Mementos](#)' and '[Last Offices](#)' section of the guideline. An information leaflet about the Procurator Fiscal Process for relatives can also be obtained from the above link.

Please see [Appendix 3](#) for Procurator Fiscal contact details.

## 9. Procurator Fiscal (PF)-Instructed Post Mortem Examination

Parental consent is not required for a Procurator Fiscal-instructed post mortem; completion of the post-mortem (PM) authorisation form is not indicated. However, it is still important for a senior member of medical staff to discuss with families what the process involves ([see section 10](#)) and to make them aware that **it may take a number of months for the results of the PM to be made available**. If it would be helpful, the Paediatric pathologists at QEUH are happy to speak to families to answer questions directly before or after post mortem.

### Process for PF-Instructed Post Mortem



## 10. Parent – Authorised Post Mortem Examination

The advantages and information accrued from a parent-authorized post mortem are considerable. Obtaining consent, however is a sensitive subject both for those requesting it and those granting it. Senior medical staff should be familiar with the process of undertaking a post mortem examination and preferably should have previously witnessed a PM before seeking consent. Ideally, the allocated neonatal nurse should be present during the discussions. A short video animation aimed to support staff seeking consent for perinatal PM can be found at <http://www.sad.scot.nhs.uk/video-wall/>

The paediatric pathologists can be contacted for advice regarding specific clinical questions that may be answered by PM, including options for limited PM.

Subject of post mortem is introduced to the family by medical staff, potentially prior to death if appropriate. A full explanation of the purpose of PM and what is involved should be given. *In addition*, 'The Post-Mortem Examination of a Child' leaflet should be given to parents

The parents should be allowed as much time as they need to consider whether or not to proceed with a post mortem examination. The paediatric pathologists at QEUH are happy to speak to families directly to answer any specific questions they may have

Parents should sign the Post Mortem Examination Authorisation form (see Appendix 14 for guidance) when they consent to Post Mortem Examination

Medical staff complete a **Perinatal Post Mortem Request** form *or* a **Post Mortem Request** form. Both of these forms are contained within the Bereavement Pack. Either is acceptable to the Mortuary Department and it is for the Medical Practitioner to decide which is appropriate to the case

Outwith QEUH, baby required to be transferred to QEUH mortuary for PM examination. Alternatively, baby can be taken home by the parents and brought back for the PM examination which usually occurs next working day (see sections [12](#) & [13](#))

Mortuary Department staff will contact the neonatal unit and request that the infant case record be sent to the Mortuary Department just prior to Post Mortem Examination being carried out.

Post Mortem Examinations are usually carried out within 2-3 working days of a death occurring

Parents should be advised that Post Mortem Examination findings will be discussed at a follow up appointment of which they will be notified within the forthcoming weeks

## 11. Mementos

### ❖ Memory Boxes

Memory Boxes can be given to the parents of very sick babies upon admission to the neonatal unit as a means of capturing important moments in their baby's journey through the unit. A variety of such boxes are available within NHS GG&&C neonatal units.

If the baby dies, the box will hold precious memories that have been built up during the baby's hospital stay such as clothes, hats, blanket, soft toys, name bands etc. Additional mementos that parents can keep are hand / foot prints, photographs and a lock of hair. If the parents do not wish to have the memory box, it is worth offering them the option for it to be given to a family member in case they change their minds in the future.

### ❖ Memento Authorisation

Verbal authorisation must be obtained from the parents before obtaining hand and footprints, photographs and locks of hair. This requires to be clearly documented in the Infant Case Record. If nursing staff request that mortuary staff obtain mementos then **written consent must be obtained**.

**In a Procurator Fiscal case, such mementos may only be obtained after the Post Mortem Examination has been carried out, however clarification should be sought.**

### ❖ Photographs

These can be taken prior to as well as following death (See [Action Point 5](#)). These can be obtained from the following sources:

**(Note: Where possible, photographs should be taken by whatever means as soon as possible after death to avoid changes taking place and parents becoming upset. In a Procurator Fiscal case requiring PM, please clarify if photographs can be taken prior to a PM Examination being carried out if possible.)**

- Parents can be encouraged to take their own photographs using their own phone/camera.
- At the QEUH and PRM sites, [Medical Illustration](#) can be contacted during office hours to take bereavement photographs.
- 'Remember My Baby' is a charity which offers parents the opportunity to have volunteer professional photographers take sensitive photographs of their babies before or shortly after death. <http://www.remembermybaby.org.uk>.
- With verbal consent from the parents, photographs may be taken using the ward digital camera, printed out and given to the parents. Parents should also be asked to give informed consent for the downloading and storage of these images on the secure clinical image database held in the Medical Illustration Department. (Refer to *SCBU Digital Camera Policy*)
- Parents may not wish photographs around the time of death, however they should be offered the opportunity to have them taken and archived in the Medical Illustration

Department for the future, should they change their minds. Written authorisation from the parents is required for this and should be accurately documented in the infant's case record.

#### ❖ **Hand/Foot Prints**

Hand and footprints can be a hugely important keepsake. These can be presented on cards or on a certificate that can be displayed in a frame if the parents wish.

Hand and foot prints can be obtained using dedicated "Babysafe" sensitised certificates and wipes. These are dry wipes, which are easy to use and leave no residue on the baby, parents or staff member's hands. Parents can be encouraged to be involved in creating a lasting memory by helping to make the image of their baby's hand and foot prints.

Full instructions for use are included along with the dry wipes and certificates.

**N.B. The hand used to hold the dry wipe and the baby's foot should not then be used to hold the certificate as fingerprints will be transferred on to the certificate.**

#### ❖ **Lock of hair**

A lock of hair can be obtained and placed in a small keepsake box which is placed in the memory box.

#### ❖ **Blanket of Love**

This blanket is embroidered with a small butterfly which represents the fragile nature of life. Hopefully the parents will have received this previously and they will be able to associate it with precious memories of their baby such as baptism or cuddles.

#### ❖ **Cot Card / Name Bands**

The baby's cot card and name bands are important keepsakes to offer parents and can be presented on a card or placed into the memory box.

All of the above mementos are very important to bereaved parents. They help to give a strong focus to their grief.

## 12. Last offices (preparing the baby's body after death)

The purpose of carrying out last offices is threefold:

- To prepare the baby's body for the mortuary respecting the family's cultural / religious beliefs.
- To minimise risk of any cross infection to relatives, healthcare workers or persons handling the deceased.
- To comply with legislation surrounding death, in particular where the death involves the Procurator Fiscal ([see Action Point 8](#))

The neonatal nurse, in partnership with the parents, ensures that the baby is treated with care and respect. Staff must remember that unless there is involvement of the Procurator Fiscal or a legal directive placing the baby under the guardianship of another named person, then the parents have full legal rights of their child and so all staff must act in accordance with parental wishes. ***Parents should be offered the opportunity to help wash and dress their baby. This may be the only opportunity they have had or will have to do so. Even in cases where the Procurator Fiscal is involved, parents may well still be able to assist with washing and dressing their baby; please discuss with the PF to clarify.***

It is vital also to remember that hospitals are public places and as such staff dealing with death must remember to respect all hospital users and members of the public

### Requirements for undertaking Last Offices

- Verification of death by doctor
- Personal Protective Equipment (Gloves & Apron)
- Identification of any factors that require additions to Standard Precautions in relation to infection control (See [NHS GG&C "Prevention and Control of Infection Manual"](#))
- Awareness of religious/cultural beliefs that necessitate alternative procedures to nurses undertaking last offices. ([See guidelines in the GG&C Faith and Belief Communities Manual on Staffnet](#))
- Knowledge of parental requests

### Location

Last Offices should be undertaken in a room that ensures privacy and has an engaged sign posted on the door. The neonatal nurse must always be aware of other hospital users in the area in order to minimise upset and distress.

The conditions under which last offices are carried out depend upon whether or not the baby's death is being reported to the Procurator Fiscal ([see Action point 8](#)).

## **Identification of the baby**

**This is of VITAL importance. Two neonatal nurses must check this identification.**

**TWO Identification Bands** should be placed on the baby, one on each arm. These bands should record the **baby's name, sex, CHI number and date of birth.**

**TWO Mortuary Identification Cards** should be placed on the baby, one on the gown/clothing and one on the outside sheet in which the baby is wrapped for transfer to the Mortuary. These identification cards should record the **baby's name, date and time of birth, CHI number, date and time of death and mother's name and address. NB If the surname of the baby is due to be changed at birth registration it would be helpful to have this name also recorded in addition.**

**ALL DETAILS SHOULD BE CHECKED WITH INFANT MEDICAL CASE RECORD AND NEONATAL NURSING NOTES.**

### **Procedure for Non-Procurator Fiscal case**

- When carrying out last offices, the neonatal nurse must wear a protective apron and gloves.
- If a Parent-Authorised Post Mortem Examination is to occur, the neonatal nurse should check with medical staff regarding removal of invasive devices and whether or not the baby can be bathed.
- Parents may specify an outfit that they wish their baby to wear and the baby can be dressed in these for transfer to mortuary.
- If a post mortem examination is requested then the baby's clothes should go with the baby to the mortuary. The mortuary staff will dress the baby following post mortem if a viewing is to take place within the hospital or mortuary. If there has been no request to view the baby, the clothes will stay with the baby and be handed to the funeral director when the baby is uplifted.
- Any clothing (shawl, babygro etc) that parents wish the baby to be dressed in or wish to be transferred with the baby should be recorded on the [Neonatal Death & End of Life Care Checklist](#) – Section 12. Any clothing not on the baby should be placed in a polythene bag.
- Any clothes to be sent with the baby should be labelled with the baby's name and CHI. These will be recorded by the mortuary staff in the Electronic Mortuary Register in the valuables section to ensure they are sent with the baby

Once the baby has been bathed, dried and dressed, the parents can be offered more time to cuddle their baby and say goodbye. Parents should be informed that other family members, siblings or friends can be involved in this if they wish.

When the parents have left the neonatal unit, the baby should be placed in a Moses basket or crib, with the head facing upright and not to the side (to prevent pooling of fluids) with their arms by their side. The baby should then be covered with a blanket.

Before the baby goes to the mortuary the neonatal nurse must ensure that

- The baby is correctly identified (as above)
- The baby should be laid in a waterproof backed sheet (such as an incopad) to ensure that there is no risk from exposure to body fluids by staff handling the baby

### **Procedure for Procurator Fiscal Case**

When a death is reported to the Procurator Fiscal (see [Action Point 8](#)), it is for the Procurator Fiscal to decide whether or not a Post Mortem Examination is required. If the baby has been an inpatient and there are no suspicious circumstances surrounding the death then there may be no requirement to restrict family members handling their baby prior to Post Mortem Examination. Each case must be assessed on an individual basis. If staff require further advice then the Fiscal Office should be contacted.

Handling of the baby should be kept to a minimum when the case is being referred to the Procurator Fiscal.

- The neonatal nurse must wear protective apron and gloves
- Invasive devices may need to be left in situ – discuss with medical staff
- Ensure correct labelling and identification of baby as per [identification guidance](#) above. This is of **vital importance**.

### **ALL DETAILS SHOULD BE CHECKED WITH INFANT MEDICAL CASE RECORD AND NEONATAL NURSING NOTES.**

- The baby should be laid on a waterproof backed sheet (such as an incopad) to ensure that there is no risk from exposure to body fluids by staff handling the baby.

### **Transport to the Mortuary**

After the parents and family have left the clinical area, the baby should be transferred to the Cold Store Facility within the neonatal unit or to the Mortuary. ([See Appendix 9 - Standard Operating Procedure for use of the Cold Store Facility within NHS GG&C Maternity Units](#)). During office hours, mortuary staff should be telephoned and informed of the pending transfer.

The Infant Case Record is **not** sent to the mortuary at this time.

If a Post Mortem Examination is required, mortuary staff will telephone the ward to request that the Infant Case Record or a discharge letter be sent to them at a later stage.

## **The role of portering staff**

The porters can be contacted to transfer the baby from the neonatal unit or Cold Store Facility to the mortuary. They will collect the baby in a carry box and take the most discreet route. The 2<sup>nd</sup> Mortuary Identification Card which is clearly displayed on the outside sheet allows portering staff to enter the baby's details into the Mortuary Department Register.

## **Transfer of babies from elsewhere to QEUH for Post Mortem**

If a post mortem is required, the baby will require to be transported from the base hospital to the QEUH mortuary for examination.

- For Fiscal-authorised PMs, transfer of the baby to the QEUH will be arranged by the Procurator Fiscal/police.
- For parent-authorised post mortems the neonatal nurse has the responsibility to phone the appropriate funeral directors informing them that the baby is to be transferred to the QEUH for PM. The baby will usually be transferred the following working day:

Princess Royal Maternity	- Cooperative Funeral Directors	0141 429 4433
Royal Alexandra Hospital	- J & W Gaudi Funeral Directors	0141 889 5285

## **Viewing of the baby following death**

If no Post Mortem Examination is to be carried out, babies will generally go to the mortuary at the hospital in which they died. In some units, babies will remain in the Cold Store Facility until uplifted by the undertakers.

Following death, parents may view their baby in the following places –

- a Chapel of Rest situated within the Mortuary Department
- a Chapel of Rest situated adjacent to the neonatal unit
- a “Quiet Room” situated within a clinical area
- at the undertakers.

The neonatal nurse should advise the parents of the most appropriate times for viewing at the Mortuary Department (i.e. during normal office hours Monday to Friday 9 - 4 pm). Viewing out-with these times may take place by prior arrangement with the hospital duty manager (contacted via switchboard). When viewing is taking place out-with normal office hours, two members of staff must accompany parents and family members for security purposes.

Arrangements for viewing at the undertakers should be made directly with them. The neonatal nurse can arrange this for the parents if requested.

If the death has been reported to the Procurator Fiscal, viewing may not be permitted. Please check with the Fiscal.

**All access to the Mortuary Department is by arrangement only.**

- **Within Office Hours:** Mortuary staff attend to all of the arrangements in the Mortuary Chapel of Rest and, if possible, a neonatal nurse known to the parents accompanies them.
- **Outwith Office Hours:**  
The neonatal nurse tending to the parents contacts the mortuary staff who will bring the baby to the Chapel of Rest or the quiet room for viewing. The duty manager is responsible for dressing the baby and checking identity. When the duty manager has the baby prepared for viewing, the ward staff can be informed and the parents brought to the chapel/ quiet room by the neonatal nurse.

If the parents are calling from home to arrange viewing, they should be advised to liaise with the Mortuary Duty Manager to arrange a suitable viewing time. In some instances, if staffing allows it may be possible for a neonatal nurse known to the parents to accompany them to the mortuary. The Duty Manager must record all visits in the appropriate register. The department must be left in the condition found and all linen discarded as appropriate. Out of hours the Duty Manager is responsible for activating the alarm system whereby security of the building is promoted.

**Repatriation to other parts of the UK or elsewhere**

In the rare circumstance where the baby's body is required to be repatriated to other parts of the UK or elsewhere, please see [Appendix 10](#).

### 13. Taking a Baby Home Directly from the Neonatal Unit - Adapted from NHS Scotland and Children's Hospice Association Scotland (CHAS) Collaborative guidance for staff to support families who wish to take their baby home after death\*

- In Scotland, unless a Procurator Fiscal post-mortem examination is required, there is no legal reason why a baby cannot be taken home straight home from the neonatal unit 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, however, is not the right choice for every family.**
- In the case of parent-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, usually the following day. When a Procurator Fiscal post-mortem examination is required parents cannot take their baby home prior to the procedure but they may still be able to take their baby home **following** the examination.
- **Documentation required prior to taking baby home from neonatal unit**
  - Two signed copies of the ['Ward Release Form'](#) (one for mortuary; one filed in notes)
  - [Medical Certificate of Cause of Death \(MCCD\)](#)
  - Taking our baby home – [Communication Checklist](#)
  - Taking our baby home: [Parent letter](#)
  - NNU contact details for parents
  - Police Scotland informed via 101 (see essential info below)
- **Communication**

Clear communication is important, and it is therefore vital that all stakeholders in the care of the family are appropriately informed in a timely fashion about the decision to take the baby home. A detailed [communication checklist](#) is available to ensure the relevant professionals are informed. **In particular, mortuary staff should be informed by telephone that the parents are taking their baby's body home directly as all of the deaths in the hospital must be registered in the Mortuary Department Register, even if the body does not subsequently go to the mortuary.**

#### Essential information to be shared with Police Scotland when calling 101:

- 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)
- Details of a contact person in the Neonatal Unit for Police to call if required

\*Further guidance on 'Taking a Baby Home' will soon be available within Scottish Neonatal MCN guidance.

#### 14. Medical Certificate of Cause of Death (MCCD) Completion

- **The Medical Certificate of Cause of Death (MCCD) Form is also known as Form 11.** A senior member of medical staff issues the MCCD soon after the baby's death. Step by step guidance as to how the MCCD should be completed can be found at <http://www.sad.scot.nhs.uk/atafter-death/death-certification/>
- If required, medical staff can seek advice from the Death Certification Review Service (DCRS) about an MCCD prior to completion. Telephone number: 03001231898.
- **IMPORTANT POINTS: Ensure that the baby's name on MCCD corresponds with the name by which the family have already registered or will register the baby on the birth registration card.**
- **Patient details should be entered in both the MCCD book AND in the 'Record of Issue'. It is important to ensure that the record of issue completed correctly matches the corresponding MCCD.**
- If possible, the MCCD is given to the baby's parents prior to them leaving the hospital, preventing needless return to collect at a later time, which can be distressing. Where necessary, funeral directors can collect the MCCD.
- The MCCD form is then taken by the family to a Registration Office to register the death, and a **Certificate of Registration of Death, also known as form 14**, is issued. This form is required in order for a burial **or** cremation to take place. The family should be informed that they may need to make an appointment at the Registry Office in advance of attending and must register the death within **8 days**.
- When a case is referred to the Procurator Fiscal, the MCCD is not issued until the Procurator Fiscal declares that there is no further interest in the case and that medical staff have been instructed of this. Thereafter, they can issue the MCCD. When the Procurator Fiscal authorises a Post Mortem Examination to be undertaken, the Pathologist undertaking the Post Mortem Examination will issue the MCCD.

## 15. MCCD Review Process and Advance Registration Application

- Under the new Certification of Death (Scotland) Act 2011, Healthcare Improvement Scotland now independently reviews a random sample of approximately 10% of all MCCDs for quality assurance purposes. (PF-reported deaths are not selected).
- MCCDs are selected for review at the point at which the families attend the Registration Office to register the death. If an MCCD is selected for review, registration cannot be completed until the review is finished. In some cases, this may mean that the family will have to return to the Registration Office to collect Form 14. In all cases, the Registrar will contact the family when the review is completed.
- There are two categories of review:
  - **Level 1 reviews** (approx. 8% of reviews)- The medical reviewer will check the MCCD and speak to the certifying doctor. This should take **one** working day.
  - **Level 2 reviews** (approx. 2% of reviews) The medical reviewer will speak to the certifying doctor and also check relevant medical records. This should take **three** working days.

### Advance Registration Application

If the baby's MCCD is selected for review yet the family would like the baby's funeral to go ahead quickly, families can apply for **Advance Registration**. The request for advance registration along with the content of the MCCD will be reviewed at the Registry Office. Usually confirmation as to whether the funeral can proceed is given within **two hours** of the request being made.

If a request for advance registration is successful, the death can be registered and the funeral can take place before the review is completed.

Advance registration can be applied for in special circumstances as follows:

- for religious/cultural reasons (for example, local tradition or faith requirements<sup>[1]</sup> to bury a person's body quickly) <sup>[1]</sup><sub>SEP</sub>
- for compassionate reasons (where delays would cause significant and unnecessary distress) <sup>[1]</sup><sub>SEP</sub>
- for practical/administrative reasons (for example, family have travelled from abroad to attend the funeral) <sup>[1]</sup><sub>SEP</sub>
- See [Appendix 4](#) for the Advance Registration Application Form

**Staff should be aware of the above process in order to inform families of what to expect when they go to register the death.**

**Further information about the MCCD review process and Advance Registration can be found at:**

<http://www.sad.scot.nhs.uk/atafter-death/the-scottish-mccd-review-process/the-review-process/>

## 16. Registration of Birth

The birth must be registered to allow registration of the death to take place. The Birth Registration Card issued in the maternity unit following the baby's birth must be taken to the Registrar's Office to allow Registration of Birth to take place. Registration of Birth and Death can take place at the same time.

### WHEN

- Routinely within 21 days of birth although in exceptional circumstances, this can be extended up to 3 months.

### WHERE

- Registration of birth can be in any district office in Scotland. If the birth occurred in Scotland it must be registered in Scotland.

### WHOM

- Either or both parents if they are married
- If the parents are unable to attend the Registrar's Office, then a relative or representative may do this providing the parents are married and the relative or representative has the correct legal documents required i.e:

#### **Marriage Certificate & Birth Notification Card**

- If the parents are unmarried, then both parents must attend. If both parents unable to attend, then each parent must sign a declaration form (available from Registrar) to enable the birth to be registered.
- The mother alone may register the birth if she has legal documentation from a court naming the father or if she does not wish father's name on the registration document.

Further information can be found at <https://www.nrscotland.gov.uk/registration/registering-a-birth>

## 17. Registration of Death

In order for a burial or cremation to take place, a death **must** first be registered.

### WHEN

- Within 8 days. In Procurator Fiscal cases this can be extended.

### WHERE

- Deaths can be registered in any district office in Scotland. If the death occurs in Scotland, it must be registered in Scotland.

### WHOM

- Any relative of the deceased
- Any person present at the death
- Legal representative
- Occupier of the property where the person died

### DOCUMENTATION REQUIRED

- Medical Certificate of Cause of Death (MCCD), also known as Form 11.
- Birth certificate

When registration of death is complete ([see section 15 re MCCD review process](#)), parents will be given **free** of charge:-

- 1. Form 14** - This form is required for the burial or cremation of a baby. Parents give this form to their funeral director. It informs the burial ground or crematorium staff that the death has been legally registered.
- 2. Form 334/S1** - This form is used for obtaining or adjusting Social Security Benefits or for National Insurance purposes
- 3. An Abbreviated Extract of an Entry into the Register of Death.** (A full copy is available for a fee)

If an urgent burial or cremation is required out-with office Hours, e.g. at weekends, public holidays etc, the family should be advised to contact their normal District Registry Office telephone number where a recorded message will give the telephone contact details of the On-Call Registrar who should be able to attend to the family's needs.

Further information can be found at <https://www.nrscotland.gov.uk/registration/registering-a-death>

## 18. Suppression of Lactation & Donation of Breastmilk

In the case of early neonatal deaths, the mother should be given information regarding suppression of lactation by discussing and giving simple advice on the benefits of wearing a supportive bra and taking simple analgesia. Where lactation is established, there is no quick solution and the mother needs to be given advice to suppress slowly by expressing enough milk to relieve fullness to keep her breasts comfortable, yet avoiding mastitis. Pharmacological milk suppression can be given to some women if within 24 hours of the birth. See [NHS GG&C 'Breast Care/Lactation management when your baby has died' guideline](#).

There is also the possibility of the mother donating milk that she has already expressed and frozen, or indeed donating milk that she continues to express following the baby's death, for as long as she feels comfortable. While some mothers may find this to be a helpful part of the grieving process, it will not be an acceptable option for others and the subject must be approached in an extremely sensitive and compassionate way. Please see <http://www.onemilkbankforscotland.co.uk> for more information about the process involved in donating breast milk. Contact Debbie Barnett at the Donor Milk Bank (via Switchboard) for further information and advice.

## 19. Inform Healthcare Team

**Points a) to e) – Medical Staff Responsibility**

**Points f) to o) - Nursing Staff Responsibility**

### a) Mortuary Department:

- Medical staff must inform the Mortuary Department staff of the death of all babies even when a Post Mortem Examination is not required or if the baby is being [taken home directly](#) from the neonatal unit.

### b) GP - Medical Staff are directly responsible for informing the mother's GP

Office Hours: Contact GP surgery directly

Out of hours: Contact **NHS 24 PROFESSIONALS LINE**

**0845 7000 666**

NHS 24 staff will fax details directly to GP surgery.

**GP's and Health Visitors must be informed as soon as possible following a neonatal death. It is distressing to all parties if this is not done.**

### c) Obstetric Consultant

- Medical Staff are directly responsible for informing the mother's obstetric consultant.

### d) & e) Referring Unit & CHAS (if applicable)

- Medical staff should, where applicable, contact the referring hospital consultant and CHAS team.

### f) & g) Post Natal Ward Staff / Community Midwife /Health Visitor:

If the mother is an inpatient in a postnatal ward, staff there should be informed of the baby's death **as soon as possible**.

If the mother is not an inpatient:

- During office hours the neonatal nurse should contact the Community Midwife Team and Health visitor directly.
- Out of hours call the **NHS 24 PROFESSIONALS LINE 0845 7000 666**  
Calling this number will ensure that the Health Visitor and Community Midwives are updated by NHS 24 staff. Remember to document the name of the call handler on the Neonatal Death & End of Life Care Checklist.

#### **h) Ronald McDonald House (QEUH site only):**

Inform staff via switchboard as soon as possible of the baby's death. This avoids awkward situations. If the parents wish to go home, they can be advised to leave their room key at reception and nursing staff will contact Ronald McDonald House staff in the morning to advise them that the room is no longer required.

#### **i) Clinical Psychology:**

The neonatal nurse should inform the clinical psychologists of all neonatal deaths.

#### **j) Audiology**

All babies should have a newborn hearing screening examination performed. If this is not carried out prior to the baby's discharge home, the Audiology Department staff will send out an appointment to the mother's home address requesting that the baby attend for hearing screening.

**It is of vital importance that the staff of this department are informed of every baby's death in the following way:**

Contact **Head Of Department for Hearing Screening** on the following telephone number **0141 451 6493** or **0141 201 1956** (A message can be left out of hours).

#### **k) Newborn Screening**

Inform Infant Newborn Screening laboratory staff of the baby's death. **0141 354 9277** or **78**

A message can be left out of hours.

## **l) Medical Records Staff**

It is **vitaly** important that medical records staff are informed of the baby's death. Details of the mother's and baby's names, hospital numbers, CHI numbers and addresses should be given in order that the associated hospital electronic systems are updated and that only appropriate appointments are sent out in the future.

## **m) Child Health**

Inform the NHS GG&C Child Health Team on 0141 277 7601 to ensure that appointment letters for vaccinations are not sent out. It is advised to do this even if the baby has not yet had any vaccinations.

## **n) Bounty Suppression Request**

Ensure that a Bounty Company Suppression Request Form is completed and forwarded to the maternity unit's Bounty Representative. The information contained on the form is treated with strictest confidence and is used solely for the purpose of removing the mother's details from the Bounty and relevant third party databases to ensure that inappropriate communications are not sent at a future date.

## **o) Offering Family Baby Box Cancellation**

Women who are due to deliver on or after 15<sup>th</sup> August 2017 will be offered a Scottish Government Baby Box. Expectant mothers are able to register at 20-24 weeks of pregnancy and their boxes will be delivered to them between 28-36 weeks. In the event of neonatal death, delivery of the box can be cancelled by calling **0800 030 8003**, and selecting option 3. The call can be made either by the family or health professionals; staff should offer to arrange cancellation on the family's' behalf. Should the Baby Box already have been delivered, neonatal staff should liaise with the community midwifery team to arrange collection of the box if this is in accordance with the family's wishes.

## 20. Funeral arrangements

### Choosing a Funeral Director

If parents decide to use the services of a funeral director, they will have to provide them with a certificate showing that the death has been registered. This certificate (Form 14) is given to parents by the Registrar when they [register the death](#). The funeral director will collect the baby from the hospital and arrange to have them brought to their own chapel of rest. Alternatively, the parents may wish their baby to come home, in which case, embalming may be required and the funeral director will arrange this.

Traditionally there can be a temptation for the father or another family member to arrange the funeral quickly in order to save the mother from any further distress. Parents can be advised that there is no rush to organise the service if they wish to take their time. This should be discussed with the parents as in many cases, at a later date, parents very often wish they had shared more of their thoughts when planning the funeral. [Hospital chaplains](#) can provide guidance in relation to the organisation of funeral services. Even if the parents have no particular religious faith, the chaplains have invaluable experience in helping parents find their way through what is a difficult time.

### Costs

Although funerals can be expensive, most funeral directors will charge significantly reduced or no fees for a neonatal death. Parents on low income or who are in receipt of income support from the benefits agency can use **Form 334/S1** which is given to them when registering their baby's death. This allows a Funeral Fund payment to be made. Parents not in receipt of benefits can be advised that if they are members of a trade union, then they can approach the trade union to request financial assistance. The majority of trade unions see this as a vital supportive role for members.

## 21. Issue Information Leaflets

### a) Chaplaincy Services Leaflet

The Chaplaincy service provides personal, religious, spiritual, emotional and practical support to parents and family members that respects their cultural values and beliefs.

The leaflet provides parents with written information about the service provided by the hospital chaplains. It also contains contact details for the hospital chaplains. Many parents may not have a religious advisor and so this provides a practical service for the parents. On an emotional level, many parents develop a bond with a hospital chaplain that they do not have with their own religious advisor because of the link to the place where their baby died. There may be times in the future when the parents may feel the need to visit the hospital and this leaflet gives them information on how to do that.

### b) SANDS

A variety of information leaflets produced by **SANDS – (The Stillbirth and Neonatal Death Society)** are available for parents.

## 22. Book of Remembrance & Remembrance Tree

**The Book of Remembrance** is situated in a designated “Quiet Room”. This can be made available at times in preparation for parents visiting. Parents should be made aware of this and invited to make an entry.

- Parents are given a draft memorial sheet
- Parents are given a leaflet entitled “Book of Remembrance: Guidelines for Parents” which gives them information on how to complete the draft memorial sheet in order to have an entry made in the Hospital Book of Remembrance.
- The neonatal nurse should insert their name and ward telephone extension number on the leaflet as a point of contact for the future.
- Read through the guidelines with parents to ensure their understanding of it.
- Advise that there is no rush to complete this form.
- One page per baby with a short message is allocated.
- One holy medal and a passport sized photograph can be included.
- When parents return the draft copy, it is forwarded to the Medical Illustration Department where staff produce the baby’s very own dedicated certificate ready to be placed into the Book of Remembrance. The certificate is collected by the member of staff who submitted it.
- A copy of the baby’s certificate will be forwarded to parents to keep if they have requested this on the guidelines form. The contact person will telephone the parents to advise them that their copy certificate is available prior to posting.

**The ‘Remembrance Tree’** is situated in the Sanctuary within RHC. Regardless of where their child has died, families are offered the opportunity to have a brass leaf dedicated to their loved one, with a small inscription of their choice. To organise a leaf, families or staff can get in touch with Aileen McConnell by email at [info@glasgowchildrenshospitalcharity.org](mailto:info@glasgowchildrenshospitalcharity.org) or by phone on 0141 212 8750.

## 23. Memorial Services

Memorial services are conducted by the hospital chaplains and are open to all family members and their friends who have lost a child from their lives. Parents should be issued with the leaflet including details of this service.

## 24. Baby’s Belongings Returned

If, following their baby’s death the parents do not wish to take the mementos home with them, they can be asked if they would like a relative to keep them on their behalf, should they choose to have them in future.

All of the baby’s belongings such as clothing, toys, cards etc should be returned to the parents or another family member.

Any mementos to be buried or cremated with the baby should be transferred with the baby to the mortuary. When the body is released to the funeral directors, they will advise as to the suitability of such mementos e.g. size of toy.

## 25. Recognition of Loss of a Multiple Pregnancy

A recent survey conducted in the North East of England showed that 9% of all multiple pregnancies result in a reproductive loss, ie a loss during pregnancy or within the neonatal period. Through the 'Butterfly Project', the Newcastle Neonatal Research Group has developed resources to help staff caring for affected families to enable better recognition and acknowledgment of the loss they have suffered, whilst still caring for the surviving sibling(s) within the neonatal unit. Staff could consider offering families use of these resources after familiarisation with the accompanying guidance **and** following careful consideration of the family's individual circumstances. Sensitive communication is required – while some will find use of the 'Butterfly Cot Card' hugely beneficial, not every parent will appreciate being identifiable as having suffered such a loss.

<http://www.neonatalresearch.net/butterfly-project---about.html>

## 26. Follow up arrangements

- Check that the address in the infant case record is the address where the parents are going to be staying in the near future.
- Ensure that telephone contact details are accurate.
- Where necessary, inform all relevant parties of any address change (medical records, neonatal secretary, update Hospital Information System).
- The Consultant Neonatologist's secretary will send parents the offer of a follow up appointment, usually around 4-6 weeks after their baby's death. At this time, which the parents will be given information regarding any Post Mortem Examination results and any questions they have will hopefully be addressed. This may be done in conjunction with the mother's obstetric consultant. Let the parents know that this will be offered and find out if the parents are happy to come back to the neonatal unit to be seen. If not, there are other options for venues. Some parents may find it distressing whilst others may feel comforted to be back.
- Ensure parents are aware they can access [Bereavement Support](#) at any time through self-referral.

## 27. Complete Documentation – Paperwork and Badger

Ensure all documentation relating to the baby's management has been completed including paperwork and computer information.

## 28. Neonatal Death Form (local forms may vary)

Ensure a Neonatal Death form is completed. This data is relevant for perinatal audit purposes. The form should be forwarded to the designated person in each unit.

**29. Ensure appropriate reporting and review of circumstances of death:**

- M&M Datix Form Completion
- Regional Clinical Governance Meeting Review
- Significant Clinical Incident (SCI) Review if appropriate
- [RCOG Each Baby Counts](#) Case Reporting
- [MBRRACE](#) reporting (will eventually include use of Perinatal Mortality Review Tool)

**30. Staff debriefing and support as appropriate.**

The death of a baby is also difficult and emotionally stressful for staff. It is important to recognise the relationships that are formed during a family's journey and the supportive role neonatal staff play. Consider offering senior staff-led 'hot' and/or 'cold' debriefs for all those involved and remember the potential for chaplaincy and/or psychology in supporting staff as appropriate.

Free and confidential [counselling services](#) are available to all NHS GG&C staff. Call 0141 201 0600 to make an appointment.

**This guideline has successfully undergone "Quality Impact Assessment"**

**Authors**

GG&C Neonatal Guideline Group

Revised 2017 Document: Lorna McKerracher & Jonathan Downie

Original 2010 Document: Claire Gonella & Janice Heggie

**Other Professionals consulted**

**Debbie Barnett**, Donor Milk Bank Coordinator

**Morag Campbell**, Consultant Neonatologist, RHCG

**David Crawford & Denise Bruce**, Procurator Fiscal Office, Crown Prosecution Service

**Sheena Docherty**, Mortuary Technician, QEUH

**George Fernie** Senior Medical Reviewer, Death Certification Review Service, Healthcare Improvement Scotland

**John Greechan**, Mortuary Services Manager, Pathology Dept, QEUH

**Neil Healy**, Specialist Organ Donation Coordinator

**Allan Jackson**, Clinical Lead for SCOTSTAR Neonatal Transport Team

**Louise Leven**, Consultant Neonatologist, RHCG

**Morag Liddell**, Senior Charge Nurse RHCG

**Frank J Lynch**, Undertaker, Frank J Lynch Funeral Directors

**Claire Mason**, Senior Nurse, PRM

**Aileen McConnell**, Community Campaigns Manager, Glasgow Children's Hospital Charity

**Helen McDevitt**, Neonatal Consultant, RHCG

**Jim Meighan**, Hospital Chaplain, RHCG

**Kristin O'Neill**, Glasgow Bereavement Service, Child Bereavement UK

**Dawn Penman**, Consultant Paediatric Pathologist RHCG

**Andrew Powls**, Consultant Neonatologist, PRM

**Evelyn Rodger**, Diana Children's Nurse, CHAS (*Co-author with Jonathan Downie of 'Taking a baby home' Guidance and 'Taking a baby home communication checklist' & 'parent letter'*)

**Blair Robertson**, Former Head of Chaplaincy, GG&C

**Document Name:**

GGC\_NeonatalDeath\_Neonates\_2017

**Implementation / Review dates:**

## Bibliography & Resources

1. [Larcher V, Craig F, Bhogal K, Wilkinson D, Brierley J. Making decisions to limit treatment in life-limiting and life-threatening conditions in children: a framework for practice. Archives of disease in childhood. 2015 May 1;100\(Suppl 2\):s1-23.](#)
2. [Death and the Procurator Fiscal: Crown Office and Prosecution Service 2015](#)
3. [Advance Registration Guidance – Healthcare Improvement Scotland](#)
4. [Data Protection Act 1998](#)
5. [NHS Scotland Caldicott Guardians:Principles into Practice: Scottish Government 2010](#)
6. [Repatriation of Human Remains from Scotland 2005](#)
7. [A Multi Faith Resource for Healthcare Staff: NHS Education for Scotland 2008](#)
8. [NHS “Code of Practice on Protecting Patient Confidentiality”](#)
9. [Support Around Death: NHS Education for Scotland 2015.](#)
10. [Practical Guidance for the management of Palliative Care on Neonatal Units – First edition, February 2014: RCPH Chelsea & Westminster NHS Foundation Trusts](#)
11. [Together for Short Lives Perinatal Pathway: Together for Short Lives 2017](#)
12. [SANDS Guide for Consent Takers – Seeking consent/authorisation for the post mortem examination of a baby](#)
13. [The diagnosis of death by neurological criteria \(DNC\) in infants less than two months old: RCPCH 2015](#)
14. [NICE Guideline 2017 – End of Life Care for Infants, Children and Young People with Life-Limiting conditions: Planning and Management](#)
15. [Child Bereavement UK](#) – Charity supporting families and educating professionals when a baby or child of any age dies or is dying, or when a child is facing bereavement
16. [SANDS](#) Stillbirth And Neonatal Death Charity

## **Appendix 1 - Bereavement Pack Contents**

1. Neonatal Death & End of Life Care Checklist
2. Guideline for Neonatal Death
3. Infant Identification Bands x 2
4. Mortuary Identification Cards x 2
5. Authorisation for the Hospital Post Mortem Examination of a Child under 12 Years of Age
6. Post Mortem Examination of a Child Information Leaflet
7. Post Mortem Examination of a Child Further Information Leaflet
8. Perinatal Post Mortem Request Form
9. Post Mortem Request Form (local forms may vary)
10. Ward Release Form
11. Death Registration Card
12. Memento Request Authorisation Form
13. Book of Remembrance Draft Sheet
14. Guidelines to completing the Book of Remembrance Entry
15. Chaplaincy Services Leaflet
16. Memorial Services Leaflet
17. Bounty Suppression Form
18. Neonatal Death Form

## Appendix 2

### NHS Greater Glasgow & Clyde Chaplaincy Services

#### NHS Greater Glasgow & Clyde Healthcare Chaplaincy Service

##### Contact Details during office hours

Royal Hospital for Children & QEUH Maternity Unit	0141 452 4017 or 4018
Princess Royal Maternity:	0141 211 4661
Royal Alexandra Maternity	0141 314 9561

**Out of hours contact with a Healthcare Chaplain is made via hospital switchboard**

**To contact the hospital priest at any time, contact main switchboard and ask for the priest to be radio-paged. If the priest is unavailable please contact Hospital Chaplaincy Service. An Imam can also be contacted via the Chaplaincy Service.**

Remember, staff can also access Chaplaincy Services for support.

## Appendix 3

### Procurator Fiscal Contact Details

- There are three Scottish Fatalities Investigation Units (SFIU) Teams in Scotland (North, East and West). SFIU West is based in the Procurator Fiscal's Office in Glasgow. The death should be reported to the SFIU team in whose area the significant event leading to the death occurred.
  - **SFIU West: Tel 0844 561 2470      Fax 0844 561 2440**
- See link below to Crown Office document for other SFIU contact details
- *'Reporting Deaths to the Procurator Fiscal - Information and Guidance for Medical Practitioners'* – *Produced by the Crown Office and Procurator Fiscal Service 2015*, available via <http://www.crownoffice.gov.uk/publications/deaths>

## Appendix 4

### Advance registration application form

This request for an advance registration is made under Section 6 of The Certification of Death (Scotland) Act 2011. Please complete all relevant fields below.

1. Name of the deceased:
2. MCCD serial number:
3. Registration district:
4. Registration office contact details:  
(main office telephone number)
5. This request for an advance registration in respect of the MCCD outlined above is being made for the following reason(s) (please tick one or more as appropriate):

Religious or cultural

Compassionate

Practical or administrative

6. Details of request:

(\*\*Please include date of funeral\*\*)

The applicant (the informant) hereby certifies that to the best of their knowledge and belief the information contained in this advance registration application form is correct.

Name:

Signature:

**Appendix 5:**

**Taking Our Baby Home: Communication Checklist (To be filed in medical notes upon discharge)**

Name of Hospital: \_\_\_\_\_

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 baby home letter: 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"/>
Any other professionals involved in family's care:

Police Scotland informed: Yes <input type="checkbox"/> No <input type="checkbox"/>
Incident number:

**Appendix 6:  
Taking Our 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 7

### Use of the Flexmort Cold Cot Cooling system (Cuddle Cot™)

- The Flexmort Cold Cot Cooling system (Cuddle Cot™) is a system used to cool a baby after death in a cot or basket, allowing families to care for and spend extended time with their baby, in the neonatal unit or at home.
- Set up instructions and troubleshooting advice are contained within the Cuddle Cot Box itself or online via this guidance from the King Edward Hospital, Western Australia. [http://www.kemh.health.wa.gov.au/development/manuals/O&G\\_guidelines/sectiona/8/a8.5.1.pdf](http://www.kemh.health.wa.gov.au/development/manuals/O&G_guidelines/sectiona/8/a8.5.1.pdf) (NB – Water, not biocide fluid is used locally)
- Further information can be obtained at <http://flexmort.com/cuddle-cots/>
- A troubleshooting video demonstrating how to resolve the potential problem of an air lock within the system can be obtained at <http://roftek.com/cuddlecot/>. If the issue cannot be resolved after following these instructions, Flexmort UK should be contacted on 08455 333561.
- If the Cuddle Cot is to be taken home, the family should be made aware that they can contact the neonatal unit should there be any problems with the cuddle cot. Neonatal units should make appropriately sensitive and individualised arrangements to have the Cuddle Cot returned to the unit when the family is ready.

**Appendix 8**

**NHS GG&C MORTUARY SERVICES  
WARD RELEASE FORM (NEONATAL)**

**This form is to be used when the body of the baby named below is to be removed from the ward in which they died by the family or a funeral director.**

Surname \_\_\_\_\_ CHI No. \_\_\_\_\_

Forename \_\_\_\_\_ Date of Birth \_\_\_\_\_

Baby to be registered as \_\_\_\_\_

Address \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

Post Code \_\_\_\_\_

Ward \_\_\_\_\_

Consultant \_\_\_\_\_

Hospital \_\_\_\_\_

Date of Death \_\_\_\_\_ Time \_\_\_\_\_

Details of Valuables / Toys

\_\_\_\_\_  
\_\_\_\_\_

**Parent/Funeral Director (Sign)** \_\_\_\_\_

**(Print)** \_\_\_\_\_

**Relationship/Name of Firm** \_\_\_\_\_

**Date** \_\_\_\_\_

**Staff Nurse/Sister (Sign)** \_\_\_\_\_

**(Print)** \_\_\_\_\_

**Date** \_\_\_\_\_

Please keep this form in the case notes and send a copy to the mortuary



## Standard Operating Procedure

### Cold Store Facility NHS GG&C Maternity Units

#### Process

This SOP defines the Operational Processes relating to the storage and subsequent transport of fetal and neonatal remains from the Cold Store Facility within the Maternity Unit to the Mortuary Department or to the care of the family.

#### Objective

The purpose of providing a Cold Store Facility within a maternity unit is

1. To facilitate the viewing of the deceased by parents and family members in an environment that allows ease of access and flexibility. Fetal and neonatal remains will be stored here for the length of time as judged appropriate to individual circumstances by the multidisciplinary team in consultation with family members. As a general guide, remains will be stored from between 1 and 3 days. Following post natal discharge of the mother, fetal and neonatal remains will be transported to the hospital mortuary. The receipt, temporary storage, viewing and collection of deceased must at all times be achieved safely and with discretion and dignity.
2. To maintain the deceased in a condition whereby maximum scientific information can be obtained from a Post Mortem Examination.
3. To limit tissue decomposition while burial or cremation arrangements are being made.

#### Principles

This SOP is required for effective management and use of the Cold Store Facility in order to

- Provide Governance of Clinical Practice within the organisation
- Provide clarity, consistency and protection of all staff handling fetal and neonatal remains
- Define accountability and responsibilities and clarify circumstances in which responsibility can be delegated
- Ensure clinical practice is in line with the regulatory framework
- Provide a training tool for new and existing staff

## Scope

This guidance applies to all healthcare staff involved in the operation of the Cold Store Facility. This SOP will be made available on the Staff Intranet as an Appendix of The Guideline for Neonatal Death and a laminated hard copy will also be displayed within the Cold Store Facility

## Roles and responsibilities

### Neonatal Nurses and Midwives are responsible for:

- Receiving a body into the Cold Store Facility
- Preparing and setting up a body for relatives to view
- Releasing a body from the Cold Store Facility

## 1 Receiving a body into the Cold Store Facility

- 1.1 Transport of the deceased from the neonatal unit or labour ward to the Cold Store Facility should be undertaken as discreetly as possible. Transport from labour ward will involve use of the designated "Baby Carrier."
- 1.2 Gloves and a plastic apron must be worn when handling bodies and when opening the fridge door. They must be removed once the body is in the fridge to avoid any risk of cross contamination of other items within the room.
- 1.3 Unit specific guidelines relating to locking of the fridge door should be adhered to. Ensure that the door of the fridge is firmly closed following access to maintain appropriate fridge temperature.
- 1.4 It is imperative that all bodies placed into the fridge are correctly identified as per approved guidelines. A mortuary identification card must be visible and attached to the outer sheet in which the body is wrapped. In addition to this, other forms of identification such as a second mortuary identification card and identification bands must be in place. (Refer to approved guidance on identification procedure in cases of stillbirth, neonatal and fetal loss.)
- 1.5 The body and any belongings that accompany the body should be placed on a vacant shelf within the fridge.
- 1.6 If there is no vacant shelf, place the body on a shelf so as to have the bodies at opposite ends of the shelf.
- 1.7 Accurate completion of documentation relating to the placement of the body within in the designated Register is imperative. This Register is located within the Cold Store Facility.
- 1.8 Communication with colleagues from the Mortuary Department must take place with regard to details of the deceased including placement within the fridge and post mortem

requirements if known. Out-with office hours, a voicemail message must be left on the Mortuary Department 'phone.

## **2 Preparing and setting up a body for relatives to view**

- 2.1 Ensure that an “Engaged” sign is posted on the viewing room door.
- 2.2 Communicate with colleagues from other departments within the maternity unit regarding use of the adjacent “Quiet Room” for viewing purposes to avoid the room being double booked.
- 2.3 Appropriate use of Personal Protective Clothing (PPE) Gloves and a plastic apron must be worn.
- 2.4 Remove the body from the fridge and take off the outer waterproof sheet in which the body is wrapped.
- 2.5 Check that the body is correctly identified.
- 2.6 Transfer the body to the viewing room and place in a crib.
- 2.7 Be cognisant of any requests the parents may have expressed in relation to dressing of the body for viewing purposes.
- 2.8 If time allows, and where appropriate, try to warm the baby’s head a little, using a hairdryer, as this helps reduce condensation forming on the face. The hands should also be warmed.
- 2.9 Set chairs around the crib so that the relatives can sit with their baby.
- 2.10 In units where the cold store adjoins the viewing room, ensure that the adjoining door is locked when viewing is taking place.
- 2.11 Afford the relatives privacy whilst also being aware of their need for sensitive support.
- 2.12 Following viewing, when the relatives have left, put on personal protective equipment and return the body to the fridge.
- 2.13 Dispose of clinical waste and used linen in line with guidance outlined in [NHS GG&C “Prevention and Control of Infection” Manual](#).
- 2.14 Wash hands.
- 2.15 Complete a “Record of viewing” sheet found in the dedicated folder within the Cold Store.
- 2.16 Remove the “Engaged” sign from the door of the viewing room following viewing.

### 3 Releasing a body from the Cold Store Facility

- 3.1 In circumstances in which a member of portering staff or a family representative is collecting a body from the cold store facility, it is the duty of the member of staff releasing the body to establish who that person is and which body they are collecting.
- 3.2 Show the porter or family representative into the viewing room.
- 3.3 Ensure that an “Engaged” sign is posted on the viewing room door.
- 3.4 Ensure that all of the necessary documentation that the maternity unit is required to produce has been completed. (Refer to appropriate guidance in relation to stillbirth, neonatal and fetal loss). Where the body is being uplifted by a family representative, ensure that 2 copies of the “Ward Release” form are completed and that other appropriate actions are carried out ([See Section 13 Guidance on Taking a Baby Home](#)).
- 3.5 Remove the body from the fridge. Gloves and a plastic apron must be worn. See “Appropriate use of Personal Protective Clothing (PPE)”
- 3.6 The staff member checks that the information the family representative has matches with the details on the mortuary identification cards and identification bands attached to the body. Care should be taken as it is possible that two or more bodies may have the same or similar names.
- 3.7 Check the condition of the body to ensure there is no undue leakage of body fluids. In circumstances where there is evidence of significant leakage of body fluids, renew the outer coverings in which the body is wrapped in order to release the body in a presentable condition. See “Appropriate cleaning of body fluid spills”
- 3.8 Ensure that in circumstances in which a body is being uplifted by a family representative, a suitable box of appropriate size is made available for transport of the body. Check with the family to ensure that in such circumstances, the family have their own means of transport and are not relying on public transport. Such boxes are stored in the cupboard in the Cold Store Facility. A baby carrier is available for use by portering staff for transfer of the body to the Hospital Mortuary.
- 3.9 Dispose of clinical waste and used linen in line with guidance outlined in [NHS GG&C “Prevention and Control of Infection” Manual](#).
- 3.10 Wash hands
- 3.11 Make sure that all personal property of the deceased ( clothes, toys, etc) is passed on with the body unless the family specifically requested otherwise.
- 3.12 Transfer the body in appropriate box / baby carrier to the viewing room where it can be released in sensitive surroundings.
- 3.13 The family representative or porter should sign and date the Register indicating that the body has been uplifted.

## Miscellaneous

- 3.14 Daily recording of the fridge temperature within the Cold Store Facility should be entered into the designated log book. Responsibility for daily recording of the fridge temperature is an operational issue that requires to be delegated appropriately within each neonatal unit. The fridge temperature should be maintained at approximately 4°C.
- 3.15 In circumstances in which the fridge malfunctions, specifics should be reported to Estates Department staff and transport of deceased to the Mortuary Department should be organised if timelines deem this as necessary following instruction from colleagues in the Estates Department.

### **Estates Department Staff are responsible for:**

- Responding to requests for assistance when notified by neonatal nursing and midwifery staff that the mortuary fridge temperature deviates from 2-6°C
- Advising neonatal nursing staff and midwives of any appropriate measures required following assessment of the above situation.

### **Facilities Staff are responsible for:**

- Responding to requests from neonatal nurses and midwives for uplifting and transport of deceased from the Cold Store Facility to the Mortuary Department.
- Completion of necessary documentation in relation to the above.
- Complying with instructions detailed within the Cleaning Schedule for the Cold Store Facility, a copy of which is available within the neonatal unit.

### **Related Documents**

- GG&C Guideline for Neonatal Death and End of Life Care
- Neonatal Intensive Care Unit Operational Policy
- Labour Ward Operational Policy

## **Approval Mechanism**

This SOP has been circulated in draft form for consultation and approval to relevant stakeholders within the Women & Children's Directorate. Comments received have been considered and incorporated as deemed appropriate.

## **Monitoring and Reporting Mechanisms**

Compliance with the content of this SOP shall be monitored via clinical audit trail and deviations from guidance shall be reported via the Datix Clinical Incident Reporting Mechanism.

## **Review Period**

The content of this SOP will be reviewed bi-annually. In addition, other criteria that may instigate a review include the following

- Analysis of a related clinical incident
- Change in legislation or Best Practice

The cascade mechanism for notifying any changes to this SOP will be facilitated via a number of routes including e-mail messages to relevant stakeholders, inclusion in Local Team Brief and discussion at unit meetings and Senior Staff Meetings.

**Original Lead Author-** Clare Gonella, Clinical Midwife Specialist

### **Individuals contributing to this SOP**

Janice Heggie, Neonatal Midwife

John Greechan, Mortuary Services Manager, Pathology Dept. RHSC, Yorkhill

Reviewed and updated by Lorna McKerracher, Neonatal Grid Trainee February 2017

### **Key contacts for further information / advice**

09.00 – 16.00: Pathology Department Staff

Out-with Office Hours: Neonatal and Labour Ward Team Leader

## Appendix 10

### Repatriation to other parts of UK or elsewhere

Every country maintains a different stance on the import of human remains and the supporting documentation required varies accordingly.

In these rare circumstances, specialist advice regarding the documentation required should always be sought. Glasgow based Frank J Lynch Funeral Directors have established themselves as one of the UK's specialist undertakers in this area. Mr Lynch is happy to be contacted for any issues relating to repatriation. Tel: 0141 339 112

<http://www.funeralsscotland.com/index.html>

The 'No Procurator Fiscal Interest' form ([Appendix 11](#)) and the 'Freedom From Infection' certificate ([Appendix 12](#)) may be required.



**“No Procurator Fiscal Interest” Form**

**To Whom It May Concern**

**Re** \_\_\_\_\_

This is to certify that the above named deceased died of natural causes on \_\_\_\_\_ within **Ward**\_\_\_\_\_ of the \_\_\_\_\_ Hospital, Glasgow.

Following discussions with the medical and nursing staff, there is no requirement for the circumstances of this death to be referred, or reported, to the Procurator Fiscal, nor are there circumstances that would require any further examination of the remains.

Having examined the body I confirm there is no cardiac pacemaker, radioactive or other implant present.

Therefore I can confirm that the body of the above named deceased can be taken from Scotland for burial or cremation without obstacle

Yours Faithfully,



**'Freedom From Infection' Certificate**

**Name of deceased:**

**Date and time of death:**    /    /    @    :    Hrs

**Ward and Hospital**

I declare that to the best of my knowledge the above named patient has no infectious disease and as such the remains pose no threat to anyone handling the body. All paperwork has been issued to allow the death to be registered and I therefore see no reason why the body cannot leave the country.

**Note:** *The section below must be completed by a Doctor who treated the above named patient during the period immediately prior to death.*

**Signature**.....

**Name (Block Capitals)**.....

**Qualifications**.....

## Appendix 13

### Anticipatory Care Planning & CYPADM

[NHS GG&C Anticipatory Care Plan for Children and Young People and CYPADM information](#)

The Children and Young Persons Acute Deterioration Management (CYPADM) Form:

<http://www.gov.scot/Topics/Health/Quality-Improvement-Performance/peolc/DNACPR/CYPADMFORM>

# Appendix 14

## Example Post Mortem Authorisation Form & Completion Guidance

**TOP COPY TO BE RETAINED BY PERSON WITH PARENTAL RIGHTS AND RESPONSIBILITIES**

**Authorisation for the Hospital Post-Mortem Examination of a Child Under 12 Years of Age**

This form is:

- to help you understand what is involved in a hospital post-mortem examination; and
- to provide a record for you and for the hospital about what you want to happen to your child if you decide to authorise a post-mortem examination.

If you wish more information, there are two leaflets. One is short, and gives important general information. Another gives more detailed information. If there is anything you do not understand, or want to know more about, please ask the hospital staff.

You should take as long as you need to think about whether you wish to authorise a post-mortem examination and what you would want to happen afterwards.

Please note: the post-mortem examination usually takes place two or three days after authorisation but (rarely) may take place later the same day.

Use patient identification or addressograph label if available

Child's name: \_\_\_\_\_  
 Date of birth: \_\_\_\_\_  
 Date of death: **Baby X's details**  
 Unit no.: \_\_\_\_\_  
 CHI no.: \_\_\_\_\_

**Section 1A. Authorisation of a full post-mortem examination**

I authorise the carrying out of a full post-mortem examination on my child, which involves internal examination of the body, and the keeping of small tissue samples as blocks and slides, samples of blood and bodily fluids, and may involve taking photographs, X-rays and scans. These will be kept as part of the medical record and may be used for audit, education, training or research, including genetic research. Genetic tests may be carried out if relevant to make a diagnosis.

**OR**

**Section 1B. Authorisation of a limited post-mortem examination**

I authorise the carrying out of a limited post-mortem examination on my child, which may involve keeping small tissue samples as blocks and slides, samples of blood and bodily fluids, and may involve taking photographs, X-rays and scans. These will be kept as part of the medical record and may be used for audit, education, training or research, including genetic research. Genetic tests may be carried out if relevant to make a diagnosis.

**OR**

**Section 1C. Authorisation of an external post-mortem examination**

I authorise the carrying out of an external post-mortem examination on my baby or child, which may involve taking:

photographs  X-rays  
 scans  small skin or muscle samples

**Section 2. Authorisation of retention and use of whole organs**

There may be benefits in removing whole organs during the post-mortem examination and retaining and using these organs afterwards. If so, you will be asked if you are willing to complete this Section. Please note: whole organs will only be removed, retained and used with your authorisation.

**2A**  I authorise the removal, retention and use of my child's organ(s) (please specify which) \_\_\_\_\_

for diagnostic purposes, as this can help to better understand the nature of the illness and provide more information about the cause of death.

I understand that blocks and slides may be made from organs retained under this Section, and I authorise the keeping of these as part of the medical record so that they can be used for audit, education, training or research.

**2B**  I authorise the removal, retention and use of the above-named child's organ(s) (please specify which) \_\_\_\_\_

for the following purposes, as this may benefit others who suffer from similar problems in the future (please tick as many as you wish):

audit  education/training  research  
 genetic research

(Note: where organs are retained under this Section, the disposal options in the next column must be completed.)

**Section 3. Other requests or wishes**

Would you like to make any other requests or set out any other wishes about the post-mortem examination or any retention or future use of tissue or organs? If no, please tick box

If yes, hospital staff should document here any special wishes you have: \_\_\_\_\_

To be completed by member of hospital staff who has discussed authorisation

I confirm that:

I have offered information to the person with parental rights and responsibilities about the procedures involved and the reasons for the investigations requested. I have offered to explain any procedures and options available in the level of detail that the person with parental rights and responsibilities wishes and have given any explanations asked for.

(If only one person with parental rights and responsibilities is present) I have asked whether there is likely to be any objection to a hospital post-mortem examination from anyone else with parental rights and responsibilities.

I have explained that unless the procedures authorised have already taken place, the authorisation given by the person with parental rights and responsibilities can be withdrawn at any time, but that withdrawal must be in writing and witnessed by one witness. An amended version of this form would then be passed to the person who would otherwise have undertaken the post-mortem examination.

Written information given:

Information leaflet  Further information leaflet  
 None  Written information declined

To be completed where whole organs were removed under Section 2:

I have discussed the options for disposal of whole organs which have been retained under Section 2, and have noted the following wishes:

the organs should be returned to the body after the examination. I have explained that this may delay the funeral.  
 the hospital should arrange for respectful disposal of the organs.  
 the funeral director should collect and arrange for respectful disposal of the organs.

Signature of member of staff \_\_\_\_\_  
 Name (block capitals) \_\_\_\_\_  
 Date \_\_\_\_\_  
 Job title \_\_\_\_\_  
 Telephone contact no. \_\_\_\_\_  
 Page no. \_\_\_\_\_

To be completed by person with parental rights and responsibilities

I have parental rights and responsibilities for **Baby X**

The post-mortem examination has been explained to me and I feel that I have been provided with enough information to give the authorisation set out in this form.

Signature: **Mother X details & signature**  
 Name (block capitals) \_\_\_\_\_  
 Date \_\_\_\_\_  
 Relationship to child (please tick appropriate box)  
 Mother  Father  Guardian  
 Contact details \_\_\_\_\_

Signature of persons witnessing authorisation (Note: there must be two witnesses to authorisation. Both are required to witness the content of the form and the signature of the person providing authorisation. Both witnesses must be present at the same time, and both must be 16 years of age or over.)

**Witness One:**  
 Signature: **Witness 1 details & signature**  
 Name (block capitals) \_\_\_\_\_  
 Date \_\_\_\_\_  
 Job title\* \_\_\_\_\_

**Witness Two:**  
 Signature: **Witness 2 details & signature**  
 Name (block capitals) \_\_\_\_\_  
 Date \_\_\_\_\_  
 Job title\* \_\_\_\_\_

**Complete EITHER Section 1A, 1B OR 1C**

**Complete where organs were removed under Section 2**

**Dr A details & signature**

**There should be a total of four DIFFERENT signatures**

- Section 1A or 1B or 1C must be completed
- Section 2A and/or 2B should be completed if the parents consent to the retention and use of whole organs
- Section 3 should be completed in relation to other requests or wishes
- Specific declarations on signature page are required to be completed by member of staff who has discussed authorisation
- Authorisation should be given by the baby's mother or father or guardian who has parental rights and responsibilities
- There should be a total of four different signatures (the authorising doctor is NOT a witness)
- The rate of errors in the postmortem consent form is very high
- If the form is incorrect it **CANNOT** be accepted and will have to be redone
- **The pathologist can be contacted for help in completing the form**