**Title:** Care of the Deceased Child - An Expected Death

**Purpose:** This policy is to inform and advise CFT staff working with deceased children and their families in a home or a community setting, where the death was expected. Guidance of the appropriate care pathway to ensure safe, consistent and quality care in the incidence of a child’s death.

<table>
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<tr>
<th>Applicable to:</th>
<th>All relevant CFT staff: Children’s Community Nursing Team, incl. Managers, Children’s Community and Diana Nurses, Children’s Home Care Team, Volunteers, Carers.</th>
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<tr>
<td>Developed by:</td>
<td>Ellie Retallack and Hayley Pocock</td>
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<tr>
<td>Ratified by and Date:</td>
<td>Sharon Linter – Director of Quality and Governance / Executive Nurse 4 June 2014</td>
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<td>Review Date:</td>
<td>December 2016 6 months prior to the expiry date</td>
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<td>Expiry Date:</td>
<td>See version control table 3 years after ratification unless there are any changes in legislation or changes in clinical practice</td>
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<td>Policy library location:</td>
<td>Clinical: Clinical Guidelines</td>
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**Related legislation and national guidance:**
- The Children Act 1989
- The Children Act 2004
- Working Together to Safeguard Children (March 2010)
- NMC Code of Conduct
- NICE guidance
- NHS specific guidance
- Department Of Health - Quality Standards for End of Life Care, When a person dies and Guidance for staff responsible for care after death (Department of Health) (England) (2008)
- Other relevant guidance

**Associated Trust Policies and Documents:**
- CFT - In the Event of a Death Policy
- CFT – End of Life Care Policy
- CFT Standard Operating Procedures (SOP’s)
- All other relevant policies and guidance
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<th><strong>Equality Impact Assessment:</strong></th>
<th>The Equality Impact Assessment Form was completed on 1 May 2014</th>
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| **Training Requirements:** | • See training strategy, relevant to role/job description.  
• All mandatory and essential training.  
• All relevant staff to read and be familiar with this guidance.  
• Specific training for CFT staff working with children in a community setting, and more particularly family homes, in the development and practice associated with this policy, where provision is available.  

*The organisation trains staff in line with the requirements set out in its training needs analysis and published in its Corporate Curriculum. Training which is categorised as statutory or essential must be completed in line with the training needs analysis and Corporate Curriculum.*  
*Compliance with statutory and essential training is monitored through the Learning and Development team with monthly manager's reports and staff individual training records twice yearly. Training reports are also submitted quarterly through the Trust Quality and Governance Committee Meeting.*  
*Staff failing to complete this training will be accountable and could be subject to disciplinary action.* |
| **Monitoring Arrangements:** | • **Monitoring arrangements for compliance and effectiveness:** This policy and guidance to be disseminated to all relevant CFT staff: Children's Community Nursing Team, incl. Managers, Children's Community and Diana Nurses, Children's Home Care Team, Volunteers, Carers. This will occur on completion on ratification. It is intended that all staff will be contacted to make them aware of the new documentation and they will be required to confirm that they have read and understood the policy and how it relates to their roles and responsibilities.  
• **Responsibilities for conducting the monitoring/audit:** The authors/team responsible for the policy would ensure annual monitoring and auditing.  
• **Methodology to be used for monitoring/audit:** Monitoring and auditing will be conducted via a questionnaire for all staff using the policy, to assess its effectiveness in practice and staff compliance.  
• **Frequency of monitoring audit:** This will take place 6 months before the policies expiry date.  
• **Process for reviewing results and ensuring improvements in performance occur:** Analysis of the completed questionnaires and review of documentation to update any necessary changes. |
| **Implementation:** | This new policy is to be disseminated to all relevant CFT staff and associated practitioners. Individual staff should take responsibility for their awareness, reading and compliance with the guidance provided. Staff to attend training, where available, about the policy development, guidance and practice implications. Updates should be made available |
to ensure best practice.

Version Control

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<td>May 2014</td>
<td>New document</td>
<td>Ellie Retallack and Hayley Pocock</td>
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<td>June 2017</td>
<td>Extended 6 months</td>
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This document can / cannot be released under the Freedom of Information Act.
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CARE OF THE DECEASED CHILD
An Expected Death

1. Summary

This policy details the recommended procedures to be followed in the immediate event of an expected child death, in the community setting. This policy is not intended guidance for unexpected child deaths, where National and local policies outline specific procedures for the sudden/unexpected death of infants and children (SUDI). However, it should be noted that even though a child has a life limiting or life threatening condition, they could also die suddenly and unexpectedly.

It has been informed by related legislation and national guidance along with associated Trust Policies and Documents – as cited above. It has also been informed by guidance such as Best Practice embodied in the NMC Publication – The Code: Standards of conduct - performance, and ethics for nurses and midwives (2008), The Gold Standards Framework (GSF), Liverpool Care Pathway, NICE guidance, NHS guidance and other related publications. Please refer to the reference list at the end of this document.

This policy and guidance should be read alongside recent Department of Health publications – Quality Standards for End of Life Care, When a person dies and Guidance for staff responsible for care after death. (Department of Health (England) (www.dh.gov.uk).

This policy sets out the key standards for Cornwall Partnership NHS Foundation Trust (CFT) staff to deliver high quality and consistent care in community settings, based on the needs of individual children, their family and carers, in line with current legislation and guidance.

This policy has been developed in consultation with a number of health, social and community care practitioners – including Community Paediatricians, Community nursing teams and managers, Cornwall Coroner, RCHT Paediatricians, Local Undertakers, Children’s Hospice South West (TBC).

The authors would like to thank ‘Together for Short Lives’ (previously A.C.T) for giving their kind permission, for us to cite and reference aspects of their comprehensive guidance series - End of Life Planning (August:2012)

2. Introduction – Aim and Scope of the Policy

This policy and practical guidance has been developed, to inform and advise those CFT staff working with children and their family or carers, immediately at the time of a child’s expected death. For the purposes of this policy, this would be when a child dies in a community setting, usually their home or a CFT led short breaks house. It aims to provide practical guidance immediately at the time of a child’s death.

There remains limited evidence or guidance surrounding care of the child at the end of life and after death. Much of our evidence base appears to be drawn from a consensus of professional practice and from the wider body of literature on child death and bereavement (Together for Short Lives: A guide to End of Life Care:2012).

The children for whom this policy is intended, are those who have previously, in most cases, been diagnosed as having a life limiting or life threatening illness or condition, i.e. They have been
identified to, and are known to the community nursing team. These children would usually be under the care of a community or in some cases an acute (hospital-based) paediatrician. Their death will be expected and in most cases planned for. They should have a care plan in place, including a ‘wishes’ document (see appendix II) – which is a county-wide agreed plan, and often a care package in place, typically based in the family home. This should clearly document the child and family’s wishes and choices in the event of their death. If the child dies in one of the short-breaks houses, the child’s care plan, should be onsite and easily obtainable. Parents should be informed and consulted immediately. See further guidance below.

3. The Verification of an Expected Death – When a Child Dies at Home or in a Community Setting

Declaring life extinct is a clinical process rather than a legal one, often referred to as verifying the death. This is an important skill, integral to the care pathway, however it should be highlighted that there is a clear distinction between verification and certification of death. Certification of death describes the legal process of completing the medical certificate of the cause of death and is essential before the death can be registered. It can only be carried out by a medical practitioner (Doctor) (see Section 4.)


Unregistered staff i.e. care staff and volunteers, would NOT be expected to make a formal verification of death. Only those registered nurses and medical practitioners with appropriate training would be expected to complete the procedure of determining whether a patient has actually passed away, by completing a physiological assessment to confirm the fact of death (Together for Short Lives, 2012).
Verification of Expected Death Pathway

Care Plan active and in place, with child and families wishes and preferences documented—taking into account spiritual, cultural and religious considerations

Documentation in place relevant to family wishes e.g. Allow Natural Death(AND) protocol, signed and dated by appropriate individuals; permission for nurse to verify expected death, signed and dated by medical practitioner

Death of the Child

For expected Death
Approval for nurses to verify death, completed. Proceed to clinical assessment. Further direction.

For unexpected Death
Call 999 for ambulance
Contact the medical practitioner
Do not move or touch the body without Document

Clinical Assessment to verify expected death by a nurse/practitioner who is competent and trained to do so:

1. Systematically assess the child for signs of life.
2. Observe for movement, swallowing and coughing.
3. Check the child does not respond to stimuli.
4. Observe for absence of respiratory effort – observe for chest wall movement by looking and feeling for the rise and fall of the chest, at the same time listening for any signs of respiration. A stethoscope can be used if available to ensure there are no breath sounds present. This should be completed for a minimum of one minute. Document observations.
5. Check for cardiac output – the carotid or femoral pulse should be palpated for a minimum of one minute. A stethoscope may be used to ensure there are no heart sounds present. This should be completed for a minimum of one minute. Document observations.
6. Check both eyes – ensure the pupils are fixed and dilated. Check both pupils are unresponsive and do not react to light with a torch.

7. Ensure that the time, place of death and persons present are fully documented.

Once initial verification has taken place, evidence suggests it is good practice to leave a short interval and recheck after this.

*If the practitioner is in any doubt or the child’s death is in any way unexpected or unexplained, death must not be verified and staff should be aware of local procedures for referring the event. Contact a medical practitioner immediately and do not move or touch the body until further advised. Document all actions and events.*

**Drug administration may be stopped – document time ceased**

*Ensure safe disposal of medicines in line with CFT Medication Management policy*

**Complete documentation – include exact time, date and place of death, who was present**

**Notification to the Medical practitioner, other relevant professionals and other family members**

**Care of the Deceased Child's body and moving the body as appropriate**

*(See separate guidance)*

**Certification and Registration of the child's death**
Certification of Death

The Law requires a medical practitioner to certify the cause of death. The law does not allow anyone other than a medical practitioner to certify the cause of death. The certificate must be completed by the registered medical practitioner who attended the child before his or her death (Coroners and Justice Act, 2009).

This process requires the doctor to complete a ‘medical certification of cause of death’ – which includes:

- A statement of the cause of death
- The date the child died
- The date the doctor last saw the child alive
- Whether they have seen the body after death

If the medical practitioner is unable to establish the cause of death, the case must be referred to a coroner or procurator fiscal (public prosecutor in Scotland) (Guidance for children’s palliative care services: Together for Short Lives, 2012.) See section 7 – referral to a coroner.

4. Communication with the Child’s Family

Relatives are certain to remember the way in which the news of the death of a family member was broken to them. The way in which the news was delivered and subsequent actions may influence the bereavement process.

Breaking Bad News

Prior to informing any family members that the child has died, it is essential to confirm the identity of the person you are speaking to.

With children receiving end of life care, the Wishes document may already have documented how the family wish to be informed / contacted if they are not present at the time of death. Staff should be familiar with their patients' wishes document.

Breaking Bad News over the Telephone

The following points should be considered before breaking bad news over the telephone:

- Whether it is appropriate to break bad news over the telephone
- Whether you are the most appropriate person to deliver the news. Consult with a colleague or line manager if in any doubt
- What knowledge the family members have of the child’s condition before death
- When the person last saw the child
- The age and health of the person
- How far the person may have to travel to reach the family home
- Language barriers, speech, hearing or language

Once the decision has been made to break the bad news over the telephone:

- It is essential to confirm that the correct child and their family members are identified
It is important to ensure you do not imply that the child is still alive at the time of the phone call if they are not, as omitting truth or facts may later appear suspicious.

Make sure you will not be disturbed or interrupted when making the phone call.

Check their location and whether they are alone.

State clearly who you are and whether you have met or spoken to them before.

Acknowledge the difficulty of having this conversation over the telephone as this will reduce the negative impact and serve as a warning shot.

Be direct and clear with the information that you give. Confirm that the death has occurred. Use the words ‘is dead’ or ‘has died’.

Be honest if they ask if the patient has died and give a brief description of what happened.

Make sure you have time to listen and answer any questions that the family may have.

Offer that they phone back later with any questions they may have.

Ascertain whether or not they would like to see the deceased child.

Document a detailed account of the conversation.

Care of the Deceased Child’s Family

The grieving process can be affected by the experiences that grieving family members go through. It is important to realise that there is no correct way for people to grieve. The response of family members is not always the same and may vary significantly. It is important for staff to be sensitive and respectful of family members at this time. A sensitive and caring approach should be adopted.

One of the most important aspects of care immediately after death is the provision of time and privacy for the family. Evidence suggests that time spent with the child after death can have a lasting effect on parental grief. It is therefore important to ensure parents do not feel rushed in the hours and days following the death of their child. Be patient as some parents are unable to accept the sad news and may cope by denying it. Denial is a form of emotional protection which often disappears when an individual is ready.

It is important to try to avoid using medical jargon. Family members do not often retain much of the information they are provided with at these times. It is important for parents to have the opportunity to choose how they and their child are cared for. In order for parents to be able to make these choices they will need all the information on the options open to them, time to understand this information and time to make their decisions. It may be necessary to reiterate information to family members. Providing them with written information may help with this as they will be able to go back and refer to this when they feel ready to.

Always be truthful when communicating with family members as honesty establishes trust between the parents and the staff member. Tell parents everything you know about the death of their child and be honest about what you do not know. Always suggest to parents that you are able and willing to find out the information you do not know. Family members should be offered time to spend with a doctor for them to ask questions and discuss events prior to death.

It is essential that a lead is taken from the family with regard to their needs. They may have religious or cultural needs they wish to demonstrate. Refer to Appendix I ‘Cultural and Religious Considerations’ for information on this. Family members may ask to see a member of the chaplaincy or ask for a specific person to be contacted. It is appropriate to offer if the family would like anyone else to be contacted. All this information should be in the child’s care plan/ Wishes Document.
Care of the Child’s Siblings

The death of a child has profound effects on their siblings. Siblings may experience a confusing myriad of emotions from resentment, about the continued focus on their brother or sister, to a sense of sadness and loss. Although parents often think it is better to protect siblings in the time leading to and after the death, in fact children are highly perceptive and tend to fabricate and fill in the gaps in their knowledge, which can lead to unnecessary anxiety. Often, siblings of the children CFT staff work with would have had input from a sibling support worker via the child’s hospice. It may be useful to check with parents to see if they require extra support at this time.

5. Who to Contact

Who to Contact when a Child Dies at Home or in a Community Setting

When a child dies at home, their GP should be notified as soon as possible. If it is out of hours, SERCO, the out of hour’s doctor should be called.

SERCO: 0845 2000227

The GP will normally visit the house and, if the death was expected, should be able to issue a certificate giving the cause of death. If the GP has seen the child within the last 14 days it is not necessary for them to come to see the deceased child, though it is usually best practice for them to come out, and is often reassuring for families. If the person did not have a GP or you do not know the name of the GP, an ambulance should be called instead. As this policy is intended to cover expected death of children known to CFT staff, calling an ambulance will rarely be necessary.

CFT on-call manager should be informed, as well as the Children’s Service Manager. If out of hours or uncertain who to call, phone Bodmin Switchboard:

01208 251300

If a doctor is not able to issue a certificate, it is because they are unsure about the cause of death. The death must then be reported to a coroner. The body will be taken to the Emergency department where the paediatric team will take the lead for the Child Death Process for an expected child death. The coroner will decide whether a post mortem will take place as part of this process.

Local policy indicates, that as soon as this process has begun, a rapid response practitioner (a specialist health visitor) will be allocated, along with a consultant paediatrician to lead the investigation.

*It is important to be aware that if an ambulance needs to be called, the Police will be automatically called too if the child is declared as dead at the scene. The ambulance crew will also try to resuscitate the child, unless there is a ‘Do not Resuscitate’ (DNR) letter signed from the consultant/GP. This documentation should be readily available and a copy should be in the child’s care plan.
What to do in the Event of a Death of a Child within the Short Breaks Service

1. If the staff member who finds the child has any doubts over whether the child is dead CPR should be commenced unless a ‘Do not Resuscitate’ (DNR) order is in place. This should be easily identified at the front of the child’s care plan, and be known to all staff working with the child.

2. An ambulance should be called immediately via 999.

3. Parents should be contacted and informed of what is happening, informing them that the emergency services have been called.

4. Their doctor should be called immediately – if out of hours doctor via SERCO should be called 0845 2000227.

5. The on call manager should be contacted and the children’s service manager should be informed. If unsure who to contact call Bodmin Switchboard: 01208 251300

6. When the doctor has confirmed the death, parents should be informed. If the parents cannot be contacted the police should be informed.

7. In the case of a sudden or unexpected death, a medical certificate will not be issued. The body will be removed for examination by The Coroner. Then the body will usually be released and a medical certificate issued, following a post mortem and inquest. A rapid response practitioner will be allocated as soon as this process begins and a Child Death Review will systematically follow. The locality manager will need to make a decision as to whether the sudden untoward incident policy is to be implemented.

8. The consultant on call should be informed as soon as possible.

9. The staff member who found the child should ensure they have completed a report alongside the team leader. This is particularly important if the death was sudden and unexpected as a coroner’s inquest will likely be held.

10. Staff must observe and follow the CFT Medication Management Policy - 'If a child dies in a short break house or special school, quarantine all their medication for 2 weeks. With a second nurse or pharmacist as witness, seal the medication in a bag or envelope, label it and store in the medicines cupboard. Record the names and quantities of the medications in the house / school diary, signed by the 2 staff. For Controlled Drugs, sign them out of the CD Register and store in a sealed labelled bag / envelope in CD cupboard. If the coroner requests the medication, ask the coroner or official representative to sign for them in the team diary. If, after 2 weeks, they have not been requested, confirm they are not required, record and destroy them in the usual way.'

11. In cases where the death certificate has been issued, the parents or their appointed representative will need to liaise with other health professionals and make arrangements for the removal of the body.

12. For children who do not live with their natural parents attention is drawn to new changes in the law effective from April 1st 1997. This means that relatives will not have to travel to the area where the death occurred in order to register the death. They can ask for details of the
death to be sent to the area where the death will be registered by providing a posted copy of the cause of death.

6. **The Care of a Deceased Child**

- The parents/carers or any other person that has legal responsibility for the child retains some rights over their child’s body after death, therefore all staff must act in accordance with the wishes of the parents. It is paramount that safeguarding of the child’s body is still an important consideration after the child has died.
- Any care of the child after death must be discussed with the parents/carers and should only be carried out with their verbal consent and co-operation, unless the child has been referred to a coroner; see section ‘Referral to a Coroner’.
- The care after death procedure should be explained to the child’s family. Parents/carers should be invited to participate in the washing and dressing of their child, whilst supporting them to do this. This encourages family centred care and provides the opportunity for closure whilst recognising that the child is still part of their family.
- The care of each child should be guided by the families’ specific requests to meet their individual cultural, spiritual and religious beliefs. Refer to the section ‘Cultural and religious considerations’. Care of the body after death may be refused depending on the religious/cultural beliefs of the family.
- Follow the child’s Wishes Document where appropriate, which should be in the child’s care plan.
- The procedure listed below should not be followed if the death has been referred to a coroner. This is because evidence must be preserved for investigation into the cause of death which may possibly involve forensic samples.

**Personal Care of the Deceased Child’s Body when an Expected Death has Occurred**

1. Gather the equipment that will be needed.

   **Equipment list:**
   - Mouth care equipment
   - Child’s own clothes – confer with family/wishes document
   - Bowl, soap, towel, cloths, brush
   - Micropore tape
   - Clinical waste bag
   - Clean sheets
   - Cannula bungs
   - Dressings, bandages, gauze
   - Nappies if the deceased child is a baby or uses them
   - Toothbrush and toothpaste

2. Personal care after death ought to be carried out within two to four hours of the person dying, in order to preserve their appearance, condition and dignity.

3. Universal precautions policies and procedures must be adhered to. Apron and gloves must be worn when handling the child’s body. If the child has a communicable disease staff and
parents should be made aware of precautions to be taken in preventing the spread of infection.

4. Remove any excess bedding and pillows.

5. At all times the dignity and respect of the deceased child should be maintained. Do not leave the body naked or exposed at any times.

6. The body should be handled gently to avoid bruising.

7. Lay the child onto their back, whilst adhering to manual handling policies and procedures.

8. The child should have a sheet placed underneath them and covering their body. A single pillow may be required to support the head as this helps to support the alignment of the body and helps the mouth to stay closed.

9. In older children consider supporting the jaw by placing a rolled up towel on the child’s chest underneath the jaw. The jaw should not be tied unless specifically guided by family members. Refer to ‘Cultural and Religious Considerations’.

10. If possible, lay the limbs out straight. Close the mouth and shut the eyes by applying light pressure to the eyelids for 30 seconds but do not force. Closure of eyes will provide tissue protection in case of corneal donation.

11. If the child has any intravenous lines or cannulae in situ these must not be removed and the sites must be secured with gauze and tape. Mechanical aids such as syringe drivers are to be removed only. Intravenous infusions should be clamped but left in place. Lines should be capped off with a bung. Lines must not be removed until confirmation has been given by a doctor that it is not a coroner’s case. In the case of an expected death it may have been clarified by a doctor prior to death and therefore lines can be removed. Any actions taken must be fully documented.

12. If the child has an endotracheal (ET) tube in situ this must not be removed until confirmation has been given by a doctor that it is not a coroner’s case. This is because cutting the tube deflates the balloon that holds the tube in position. The increased mobility may enable the ET tube to become displaced during the handling of the body and any possibility of movement will lead to confusion should the coroner need to investigate this via a post mortem. In the case of an expected death it may have been clarified by a doctor prior to death and therefore the tube can be removed. All actions taken must be fully documented.

13. In infants/younger children nappies should be used to retain any urinary secretions. If the child has a catheter in situ the bladder should be gently drained by pressing on the lower abdomen. The catheter and catheter bag must be left in situ. This is because the body can continue to secrete bodily fluids after death.

14. Pack any orifices with gauze if fluid secretion continues or is anticipated. If excessive leaking of bodily fluids occurs consider the use of suctioning. Open drainage sites may need to be sealed with an occlusive dressing. If a post mortem is required, existing dressings must be left in situ and covered and drainage tubes must be left in situ. Leaking orifices pose as a health hazard to all people coming into contact with the body.
15. If the child has any jewellery on check with the child’s parents/carers if they would like it to be removed before doing so. If they would like it to be removed give this to the parents/carers to retain. Refer to the section ‘Cultural and religious considerations’. If any jewellery is removed or remains on the child this should be fully documented.

16. The child’s body should be washed and dressed. This is for hygiene and aesthetic reasons, as a mark of respect and parents/carers should be invited to participate in the washing and dressing of their child, whilst supporting them to do this. Parents may request that the child is not washed for religious and cultural reasons.

17. If necessary clean the child’s mouth using a foam stick to remove any debris and secretions. Clean the child’s teeth using their own toothbrush and toothpaste. This is for hygienic and aesthetic reasons.

18. Brush the child’s hair and arrange it into the preferred style (if known) to help guide the funeral director for final presentation.

19. Parents should be asked if they have any specific preferences with regard to what they would like their child to be dressed in or if there is anything they would like to stay with their child such as a toy or a photograph.

20. A photograph, hand and foot prints and a lock of the child’s hair, or other appropriate mementoes, should be offered to the parents. If mementoes are taken these should be fully documented. These keepsakes are important in acting as a memory of the child for the family. Should the family initially decline the offer of such mementoes staff can, with the parents consent, offer to keep these in the child’s file should the family change their mind at a later date.

21. All actions taken must be fully documented.

22. Dispose of equipment according to infection control principles. Remove gloves and aprons. Wash hands with soap and water following the six-stage Ayliffe technique (Appendix IV). This is required to minimise the risk of cross-infection and contamination.

23. A white sheet should be placed over the body with the head out and a hand should sit outside of the sheet so that family members can hold the child’s hand if they wish to.

24. The child’s body should be placed in a room which is cool but not too cold and well ventilated. Windows may need to be open and ensure radiators in the room are turned off. The body’s core temperature will take time to lower and therefore refrigeration within four hours of death is optimum. Guidelines suggest that the body should be placed in a room with the temperature being kept below 12°C, preferably between four and eight degrees. This however may not be tolerable for relatives who wish to be in the room for extended periods and there are now cold beds and blankets that are available which can offer effective cooling systems. Children’s hospices are using Flexmort, which is a manufacturing company that provides innovative mortuary systems for the cooling and storage of the deceased. Air-conditioning units may also be used to ensure the room is kept cool. The funeral director is also able to give support and advice about keeping the child’s body at home in the most appropriate environment.
25. The family should be given the opportunity to view the body if they wish to. They should be prepared for what they may see. Ensure the room is clean and tidy and that they are provided with a comfortable and private place to spend time with their child after death.

26. The body should be monitored as an ongoing process for any deterioration. Monitoring should be continued in consultation with the funeral director until the body is transferred to the coffin.

27. Viewing the body after three days after death is not recommended due to the natural deterioration of the body that takes place after this time.

7. Referral to a Coroner

In some circumstances doctors cannot immediately issue a death certificate and they are then obliged to inform the Coroner. Usually this occurs because the doctor is uncertain of the cause of death, or the death has occurred very suddenly. The Coroner will then decide whether it will be necessary to have a post mortem examination. If a post-mortem is requested by the Coroner, this is a legal requirement and it will be carried out regardless of the family’s wishes. The Coroner’s Office will contact the family to inform them when the death certificate is available for collection. If the coroner decides to proceed to an inquest the death certificate cannot be issued until after this process is completed. This could take several months following the child’s death.

If the child has been referred to a coroner and a post mortem is required there are specific activities which must not be carried out by parents or staff. Permission must have been gained from the coroner to undertake any activities:

- Lines/tubes must not be removed until confirmation has been given by a doctor that it is not a coroner’s case. In the case of an expected death it may have been clarified by a doctor prior to death and therefore lines/tubes can be removed.
- Last offices should not be performed, do not wash the child, change their clothes or bed linen.
- All actions taken must be fully documented.
- Consent does not need to be obtained from the parents/carers if a coroner’s post mortem is required, although the coroner will consult with the parents/carers before a decision has been made.

8. Registering the Death

It is a legal requirement to register all deaths within 5 days in England and Wales and within 8 days in Scotland. It is necessary to register the death before the funeral arrangements can be arranged. If necessary assist the family in finding out where the nearest registry office is. The child’s GP surgery should have this information. The death must be registered in the district where the child dies. There is no cost for registration.

Practically, the procedure is usually pretty straightforward. But it can be very upsetting for some people, so support for the family should be available.

In England, all deaths must be reported to the Child Death Overview Panel (CDOP). In cases of expected death there is a detailed process to follow and forms to complete. If a death is unexpected or there is any doubt surrounding the death, nurses and carers must be aware of local procedures.
If there are special situations, such as a post mortem, registering a death may involve more paperwork and may take a bit longer.

A relative may be the best person to register the death. If this isn’t possible, someone else can do it but they will need to discuss this with the registry office.

It will be necessary to have:

- The completed child’s medical certificate of cause of death (death certificates are needed for administrative purposes; if there has been a post mortem, no medical certificate will be required)
- The full name, address, date and place of birth, of the child who has died
- The names of the parents, their home addresses and occupations
- The date and place of death
- An NHS medical card if possible
- The child’s birth certificate

If the death has been reported to the coroner or procurator fiscal, additional information will be required. Advice can be sought from the local coroner’s office:

Cornwall Coroner - 14 Barrack Lane, Truro, Cornwall. TR1 2DW
01872 261612

Once they complete these details the Registrar will issue a certificate for burial or cremation, depending on what the family decide to do. This certificate needs to be given to the funeral director so they can complete the funeral arrangements. This certificate is free of charge but families may need to pay a small fee for a certified copy. This will be required if the family wishes to bury their child abroad.

9. **Transfer of the Deceased Child**

The funeral director will usually undertake transfer of the deceased child within a community setting. If arrangement has been made to transfer the child to a hospice, or hospital setting, the Police should be notified that the deceased child is being transported on public highways network, as there are laws on the transportation of the deceased.

Ensure the Hospice have been made aware of the child’s death and the plan for them to be transferred.

10. **Arranging the Funeral**

Arranging a child’s funeral can be overwhelming. The following may be a helpful list for families:

- Choosing a funeral director
- Choosing the type of funeral
- Costs of a funeral
- The child and family wishes
- Having a private or public funeral
- Having flowers or donations
Please see Appendix VI for further information that could help direct families through the Funeral/burial process, if they request support with this.

11. Organ Donation

If the family have agreed to donate their child’s organs, it should be explicitly recorded in the child’s care plan. The National Blood Service Tissue Coordinator (24hrs) will need to be contacted to discuss whether the child’s tissues could be used if the child has died at home or in a community setting, as there may be a limitation to which organs can be used.

Corneas (usually children over 3, but others may be considered) and Heart Valves (can usually only be used from cancer patients if they have not been treated with anthracyclines) can be used within the first 24 hours following a child’s death.

If families have decided to go ahead with donation, at the time of their child’s death:

- The tissue coordinator should already have details from the child’s GP or another health professional involved in the child’s care.
- If the donation is possible parents will be asked to give verbal consent over the telephone to the Tissue Coordinator. The message will be recorded.
- Arrangements will be made for the child to go to a suitable place for the tissues to be retrieved. This could be a hospital mortuary, funeral directors or similar setting. The child may then be returned home or to the hospice, as is the families wish.

National Blood Tissue Service Tissue Coordinator 0765 918 0773 – 24 hours

12. Removal of Equipment from the Family Home

The child’s Community Nurse or the office administrator (CFT Community Nurses office - 01872 246930) should be contacted to arrange removal of NHS equipment from the family home. Staff should be considerate and allow an appropriate amount of time before they arrange for this to happen, in order to show courtesy to the grieving family.

13. Advice and Support – for Staff and Families

Advice and Support for Staff

Staff who have been involved with a child who has died should be given the opportunity to discuss their feelings about the death during a debriefing session.

The Children’s Community Nursing Team currently has an allocated Psychologist who can be contacted via the Community Team Secretariat: 01872 246930.

As soon as possible after the event staff should arrange to meet with their manager to discuss what has happened.

It is important that staff speak to someone they feel they can trust and not withhold their feelings/concerns as this could be detrimental later.

A bad reaction can be characterised by severe distress lasting more than two days. These could include recurrent intrusive images of the deceased child, poor sleep and nightmares, being hyper
vigilant or irritable. If these signs develop, staff should inform their manager who will be able to arrange counselling through the occupational health department.

14. **Useful Contacts**

- Bereavement Advice Centre
- The Child Bereavement Trust
- Cruse Bereavement Care – Available at: [www.crusebereavementcare.org.uk](http://www.crusebereavementcare.org.uk)
- London Bereavement Forum
- Parent Channel: Bereavement
- Compassionate Friends – 0117 953 9639. Available at: [www.tcf.org.uk](http://www.tcf.org.uk)
- Child Death Helpline – 0800 282 986. Available at: [www.childdeathhelpline.org.uk](http://www.childdeathhelpline.org.uk)
- Childhood Bereavement Network – 0207 843 6309. Available at: [www.childhoodbereavementnetwork.org.uk](http://www.childhoodbereavementnetwork.org.uk)
- Winston’s Wishes – A leading childhood bereavement charity – The largest provider of services to bereaved children, young people and their families in the UK. Available at: [www.winstonwish.org.uk](http://www.winstonwish.org.uk)

15. **References**


CFT – In the Event of a Death Policy

CFT – End of Life Care policy

CFT – Medication Management Policy

Department of Health (DH) (2008), *Quality Standards for End of Life Care, When a Person Dies and Guidance for Staff Responsible for Care after Death*, Department of Health: England.


National End of Life Care Programme and National Nurse Consultant Group (Palliative Care) (2011) Guidance for Staff Responsible for Care after Death (Last Offices).


16. **Acknowledgments**

Together for Short Lives Registered Charity No. 1144022
Children’s Hospice South West – Little Bridge House
Naomi House Hospice – Winchester
Penhalligan Friends Registered Charity

17. Contributors

- Dr. Emma Carlyon – Cornwall Coroner
- Dr. Julia Harvey – Consultant Paediatrician, Named Doctor for Child Death Reviews
- Steve Turner – Medicines Management CFT
- Andrew Richards - AC Richards and Son Funeral Directors
- Kevin Tregunna – L J Tregunna Funeral Directors
- Karen Berriman – Clic Sargent Outreach Nurse RCHT
Appendix 1 – Cultural and Religious Considerations

- It is important for any religious beliefs of the family to be identified prior to death. This should be documented within the child’s wishes document.
- It is important to note that individual requirements will vary even among members of the same faith.

<table>
<thead>
<tr>
<th>Religion</th>
<th>Beliefs</th>
</tr>
</thead>
</table>
| Christianity | - Relatives may request a hospital chaplain or priest from their own church to offer prayers.  
- Roman Catholic families may request the presence of a Roman Catholic priest.  
- If a baby is receiving end of life care baptism may be required.  
- There are no objections to post mortems or transplants. |
| Buddhism   | - A request may be made for a Buddist monk (Bhikku) or nun (Sister) to be present.  
- The body should not be moved for at least one hour as prayers have to be said to the deceased.  
- As there are a number of different schools of buddism, relatives should be contacted for advice on how the body should be treated.  
- The relatives may request for the body to be left for a period of time, whilst prayers are said.  
- They may require time and space for meditation, which is often a considerable amount of time.  
- A side room is essential as they believe that the state of mind at death influences the state of rebirth.  
- They may be unhappy with pain relieving drugs because of the need to maintain a clear mind and stop meditation prior to death.  
- They like to maintain a calm acceptance of death.  
- No special rituals after death.  
- Cremation is preferred.  
- There are unlikely to be any objections to post mortems or transplants.  
- The body should be wrapped in a plain sheet. |
| Hinduism   | - Relatives may request the services of a priest during the last stages of life.  
- Where possible the body should not be handled prior to informing the relatives.  
- Hindu’s often prefer staff to be of the same sex as the patient to handle the body.  
- The family usually remain with the deceased and the eldest son should be present – this may just be in the case of an elders death, but just be mindful of this.  
- Relatives may request that the body is placed on the floor near to mother earth before death occurs. |
<table>
<thead>
<tr>
<th>Islam</th>
<th>Judaism</th>
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<tbody>
<tr>
<td>- The deceased should always be covered with a plain white sheet.</td>
<td>- Many Jews prefer for someone from the Jewish faith to touch the body.</td>
</tr>
<tr>
<td>- Support the jaw.</td>
<td>- A dying person should not be left alone.</td>
</tr>
<tr>
<td>- Do not remove sacred threads or jewellery.</td>
<td>- Families may wish to sit with their relative during the last days or hours.</td>
</tr>
<tr>
<td>- Cremation usually occurs soon after death, therefore a speed completion of the death certificate will aid this process.</td>
<td>- If a patient or his/her relatives wish to see a Rabbi, then the patient’s own Rabbi should be the first to be called.</td>
</tr>
<tr>
<td>- May receive comfort from hymns and readings from the Bhagavad Gita (1962, Chapters 2, 8 and 15) which family/relatives read.</td>
<td>- Traditionally the body is left for around 8 minutes before being moved whilst a white feather is placed across the lips and nose to detect any signs of breathing.</td>
</tr>
<tr>
<td>- A piece of sacred Kusha grass may be placed under the bed by relatives.</td>
<td>- The body should be handled as little as possible.</td>
</tr>
<tr>
<td>- The leaves of the tulsi plant and Ganges water might be placed into their mouth if dying, which is obtained from their Temple.</td>
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<tr>
<td>- Post mortems would only be allowed if it is a legal necessity as they are thought to be disrespectful to the deceased.</td>
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<tr>
<td>- There are no objections to organ transplants.</td>
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</table>
- The body should not be washed and should remain in the clothes in which they died in.
- The family may request that the jaw is tied up.
- It is often seen as a religious duty for the Jewish people to stay with the body until burial.
- Once death is established the son or nearest relative (if present) may wish to close the eyes and mouth, straighten the body and bandage the jaw.
- Post mortems are only permitted if legally required.
- There are no religious objections to transplant.

**Sikhism**

- Family and friends are normally present and they may read from the Psalm of Peace (may sing or read).
- No loud lamentation is encouraged.
- The eldest son may wish to take the lead for the last offices.
- Do not remove the ‘5 Ks’ which are seen as personal, sacred objects. These include:
  - Kesh: do not remove the head covering. For adults this is: Men = turban. Women = duppata.
  - Kanga: do not remove the semi-circular comb which fixes hair.
  - Kara: do not remove any special bracelets.
  - Kaccha: do not remove any special shorts worn as underwear. Seek advice from the family if soiled.
  - Kirpan: do not remove miniature sword if worn.
- The deceased is washed and dressed, complete with the five K’s and the body taken home so the friends and relatives can view it before the funeral which will be a cremation.
- There are no objections to post mortems or transplants.

**Jehovah’s Witnesses**

- No special rituals with the care of the dying.
- Post Mortems and organ transplants are based on the individual’s choice.
Advance care planning with families of children with life-limiting conditions is possible months or years before the end of life. Advance decisions evolve over time through the development of a trusting relationship and an ethos of shared decision making. *

This document is offered as a guide, to be used by any member of the Healthcare Team in co-ordination with colleagues, in response to family needs and requests. These are difficult but necessary discussions and this guidance is offered to support the process. Staff should not feel under pressure to complete every aspect of the form by a certain time or at one sitting, but to be led by the needs of the family as to which parts need to be discussed or reviewed – with whom, where and at what time.

Staff should aim to offer all families an opportunity to talk about end of life issues (concerns or wishes) but with the awareness that in some cases, families will not want to take this up, or may need more time before they are ready to do so. A list of information resources and contacts can be found on the last page of this document.

Begin by asking yourself the following questions:

- Would you be surprised if this child died prematurely due to a life-limiting illness?
- Would you be surprised if this child died within a year?
- Would you be surprised if this child died during this episode of care?
- Do you know what the child’s and family’s wishes are for the end of life?

If the answer to any of the above questions is “No”, this guidance is relevant.

The next steps are to:

- Find out who else is involved in the care of the child & family, e.g. a palliative care service.
- Find out if the family have already discussed an End of Life and/or resuscitation plan.

(Prompt: ‘has anyone had a discussion with you about what you would like to happen if your child becomes seriously ill?)

If the family already have a plan, you may wish to review it with them, to ensure that it is still relevant or to update it if required. If there is no plan, you can use any or all of the following pages to document the discussions using the templates, and the suggestions in the table below, as a guide.

The first page of the document should always contain general information about the child and family.
<table>
<thead>
<tr>
<th></th>
<th>CHILD</th>
<th>FAMILY</th>
<th>OTHERS</th>
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<tbody>
<tr>
<td>WISHES DURING LIFE</td>
<td>e.g. special holiday</td>
<td>e.g. family holiday</td>
<td>e.g. fundraising</td>
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<tr>
<td>PLANS FOR WHEN YOUR CHILD BECOMES UNWELL</td>
<td>e.g. treatment options</td>
<td>e.g. what may happen?</td>
<td>e.g. visiting</td>
</tr>
<tr>
<td>ACUTE LIFE THREATENING EVENT</td>
<td>e.g. preferred place of care,</td>
<td>e.g. treatment options</td>
<td></td>
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<tr>
<td>AFTER DEATH</td>
<td>e.g. funeral preferences</td>
<td>e.g. spiritual &amp; cultural wishes</td>
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</table>

After discussion with the family, please ensure that a copy of the plan is included in all medical notes and a copy is given to the family, the child’s GP & all other relevant services.

GENERAL INFORMATION

Name:

Date of birth:

Name of parents:

Name and age of siblings:

Address:

Telephone No:

Diagnosis & background summary:

Key professionals involved:

<table>
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<tr>
<th>Name</th>
<th>Position Held</th>
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<tr>
<td>Professional [Name &amp; job title]</td>
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<tr>
<td>Date</td>
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<tr>
<td>Updated on (new date)</td>
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</tbody>
</table>
## WISHES DURING LIFE

<table>
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<tr>
<th>Name:</th>
<th>Date of Birth:</th>
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Child's wishes during life:

Family wishes during life:
**Other’s wishes during life:** [e.g. school friends, siblings]

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<tr>
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<td>Date</td>
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<td>Updated on (new date)</td>
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</table>
## PLANS FOR WHEN CHILD BECOMES MORE UNWELL

**Name:**

**Date of Birth:**

**What may happen?**
E.g. deteriorating mobility, feeding, cognitive function, worsening seizures.

**Preferred place of care:**

**Preferred treatment options:** (Indicate if not applicable or inappropriate)

- Antibiotics - e.g. Oral / IV / ‘Portacath’
- Feeding - e.g. NG tube / gastrostomy
- Respiratory Support - e.g. mask ventilation
- Seizure Management Plan

If child deteriorates further, preference(s) for place of death & people present.

Inform Ambulance Service if DNA CPR has been agreed and child is going/at home.

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<tr>
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<tr>
<td>Date</td>
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<td>Updated on (new date)</td>
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</table>
# PLANS FOR CARE DURING AN ACUTE LIFE-THREATENING EVENT

<table>
<thead>
<tr>
<th>YES</th>
<th>NO</th>
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<tbody>
<tr>
<td>Oxygen via face mask/nasal cannulae</td>
<td>□</td>
</tr>
<tr>
<td>Airway management using oral/nasopharyngeal airway</td>
<td>□</td>
</tr>
<tr>
<td>Bag &amp; mask ventilation</td>
<td>□</td>
</tr>
<tr>
<td>Endotracheal tube &amp; ventilation</td>
<td>□</td>
</tr>
<tr>
<td>External cardiac compressions</td>
<td>□</td>
</tr>
<tr>
<td>Defibrillation &amp; adrenaline</td>
<td>□</td>
</tr>
<tr>
<td>Advanced life support requiring PICU admission [Including inotropic drugs and advanced renal replacement therapy]</td>
<td>□</td>
</tr>
</tbody>
</table>

**Please give further details if required:**

---

**Other issues discussed:**

If child deteriorates further, preference(s) for place of death & people present.

Inform Ambulance Service if DNA CPR has been agreed and child is going/at home.

**This page discussed by:**

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<tr>
<td>Date</td>
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<tr>
<td>Updated on (new date)</td>
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</tbody>
</table>
### WISHES FOR AFTER DEATH

**Preferred place of care of child’s body:**

**Funeral preferences:**

[Seek detailed information or further advice if needed]

**Spiritual & cultural wishes:**

**Other child & family wishes:** e.g. what happens to possessions?

**Organ & tissue donation:**

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**This page discussed by:**

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<tbody>
<tr>
<td>Professional [Name &amp; job title]</td>
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<tr>
<td>Date</td>
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<tr>
<td>Updated on (new date)</td>
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</tbody>
</table>
A User's Guide and Family Information sheet are available to support the use of the ‘Wishes’ document. These are available on request from;

Francis Edwards, Paediatric Palliative Care Liaison Nurse, 07785 333014 francis.edwards@UHBristol.nhs.uk
Antonia Beringer, Senior Research Fellow, UWE Bristol 0117 328 8209 antonia.beringer@uwe.ac.uk

Other resources:
1. Together for Short Lives (The Association for Children’s Palliative Care and Children’s Hospices UK http://www.togetherforshortlives.org.uk/
Since April 1st 2008, there has been a statutory requirement to investigate unexpected and unexplained children's deaths. The website summarises these processes.
5. CLIC-Sargent (Cancer and leukaemia in childhood) leaflets/booklets, including; ‘When there is no Longer a Cure’, ‘When our Child Has Died’, ‘Living Without your Child’, available at www.clicsargent.org.uk

This Child & Family Wishes Document was developed by members of the Service Improvement Network Project (listed below) to support, and promote, End of Life planning for children with life-limiting conditions.

<table>
<thead>
<tr>
<th>Name</th>
<th>Role/Position</th>
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</thead>
<tbody>
<tr>
<td>Antonia Beringer</td>
<td>Senior Research Fellow/project facilitator, University of the West of England, Bristol</td>
</tr>
<tr>
<td>Suzanne Bingley</td>
<td>Service Improvement Facilitator, Bristol PCT</td>
</tr>
<tr>
<td>Jan Berry</td>
<td>Charlton Farm Children’s Hospice Nurse</td>
</tr>
<tr>
<td>William Booth</td>
<td>Modern Matron PICU, University Hospitals Bristol NHS Trust (UHB)</td>
</tr>
<tr>
<td>Pam Cairns</td>
<td>NICU Consultant, UHB</td>
</tr>
<tr>
<td>Avril Dafydd-Lewis</td>
<td>Chaplain, UHB</td>
</tr>
<tr>
<td>Nicola Eaton</td>
<td>Director Children’s Palliative Care Research, CCAH</td>
</tr>
<tr>
<td>Karen Forbes</td>
<td>Consultant in Palliative Medicine, UHB</td>
</tr>
<tr>
<td>Name</td>
<td>Position</td>
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</tr>
<tr>
<td>Fiona Finlay</td>
<td>Community Paediatrician, Bath &amp; NE Somerset PCT (B&amp;NES)</td>
</tr>
<tr>
<td>James Fraser</td>
<td>PICU Consultant, Designated Doctor for Unexpected Deaths in Childhood, UHB</td>
</tr>
<tr>
<td>Mary Gainsborough</td>
<td>Community Paediatrician, UHB</td>
</tr>
<tr>
<td>Nicky Harris</td>
<td>Medical Director, Charlton Farm Children’s Hospice</td>
</tr>
<tr>
<td>Helen Prescott</td>
<td>Clinical Psychologist, Lifetime Service, B&amp;NES PCT</td>
</tr>
</tbody>
</table>

Document version 28.11.2011
Appendix 3 – Verification of Expected Death Pathway

Care Plan active and in place, with child and families wishes and preferences documented—taking into account spiritual, cultural and religious considerations

Documentation in place relevant to family wishes e.g. DNR protocol, signed and dated by appropriate individuals; permission for nurse to verify expected death, signed and dated by medical practitioner

Death of the Child

For expected Death
Approval for nurses to verify death, completed. Proceed to clinical assessment.

For unexpected Death
Call 999 for ambulance
Contact the medical practitioner.
Do not move or touch the body without further direction.
Document.

Clinical Assessment to verify expected death by a nurse/practitioner who is competent and trained to do so:

1. Systematically assess the child for signs of life.
2. Observe for movement, swallowing and coughing.
3. Check the child does not respond to stimuli.
4. Observe for absence of respiratory effort – observe for chest wall movement by looking and feeling for the rise and fall of the chest, at the same time listening for any signs of respiration. A stethoscope can be used if available to ensure there are no breath sounds present. This should be completed for a minimum of one minute. Document observations.
5. Check for cardiac output – the carotid or femoral pulse should be palpated for a minimum of one minute. A stethoscope may be used to ensure there are no heart sounds present. This should be completed for a minimum of one minute. Document observations.
6. Check both eyes – ensure the pupils are fixed and dilated. Check both pupils are unresponsive and do not react to light with a torch.
7. Ensure that the time, place of death and persons present are fully documented. Once initial verification has taken place, evidence suggests it is good practice to leave a short interval and recheck after this.

*If the practitioner is in any doubt or the child’s death is in any way unexpected or unexplained, death must not be verified and staff should be aware of local procedures for referring the event. Contact a medical practitioner immediately and do not move or touch the body until further advised. Document all actions and events.*

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**Drug administration may be stopped – document time ceased**

*Ensure safe disposal of medicines in line with CFT Medication Management policy*

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**Complete documentation – include exact time, date and place of death, who was present**

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**Notification to the Medical practitioner, other relevant professionals and other family members**

---

**Care of the Deceased Child’s body and moving the body as appropriate (see separate guidance)**

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**Certification and Registration of the child’s death**
Appendix 4 – Personal Care of the Deceased Child's Body when an expected death has occurred

1. Gather the equipment that will be needed.

   **Equipment list:**
   - Mouth care equipment
   - Child's own clothes – confer with family/wishes document
   - Bowl, soap, towel, cloths, brush
   - Micropore tape
   - Clinical waste bag
   - Clean sheets
   - Cannula bungs
   - Dressings, bandages, gauze
   - Nappies if the deceased child is a baby or uses them
   - Toothbrush and toothpaste

2. Personal care after death ought to be carried out within two to four hours of the person dying, in order to preserve their appearance, condition and dignity.

3. Universal precautions policies and procedures must be adhered to. Apron and gloves must be worn when handling the child's body. If the child has a communicable disease staff and parents should be made aware of precautions to be taken in preventing the spread of infection.

4. Remove any excess bedding and pillows.

5. At all times the dignity and respect of the deceased child should be maintained. Do not leave the body naked or exposed at any times.

6. The body should be handled gently to avoid bruising.

7. Lay the child onto their back, whilst adhering to manual handling policies and procedures.

8. The child should have a sheet placed underneath them and covering their body. A single pillow may be required to support the head as this helps to support the alignment of the body and helps the mouth to stay closed.

9. In older children consider supporting the jaw by placing a rolled up towel on the child’s chest underneath the jaw. The jaw should not be tied unless specifically guided by family members. Refer to ‘Cultural and Religious Considerations’.

10. If possible, lay the limbs out straight. Close the mouth and shut the eyes by applying light pressure to the eyelids for 30 seconds but do not force. Closure of eyes will provide tissue protection in case of corneal donation.

11. If the child has any intravenous lines or cannulae in situ these must not be removed and the sites must be secured with gauze and tape. Mechanical aids such as syringe drivers are to be removed only. Intravenous infusions should be clamped but left in place. Lines should be capped off with a bung. Lines must not be removed until confirmation has been
given by a doctor that it is not a coroner’s case. In the case of an expected death it may have been clarified by a doctor prior to death and therefore lines can be removed. Any actions taken must be fully documented.

12. If the child has an endotrachael (ET) tube in situ this must not be removed until confirmation has been given by a doctor that it is not a coroner’s case. This is because cutting the tube deflates the balloon that holds the tube in position. The increased mobility may enable the ET tube to become displaced during the handling of the body and any possibility of movement will lead to confusion should the coroner need to investigate this via a post mortem. In the case of an expected death it may have been clarified by a doctor prior to death and therefore the tube can be removed. All actions taken must be fully documented.

13. In infants/younger children nappies should be used to retain any urinary secretions. If the child has a catheter in situ the bladder should be gently drained by pressing on the lower abdomen. The catheter and catheter bag must be left in situ. This is because the body can continue to secrete bodily fluids after death.

14. Pack any orifices with gauze if fluid secretion continues or is anticipated. If excessive leaking of bodily fluids occurs consider the use of suctioning. Open drainage sites may need to be sealed with an occlusive dressing. If a post mortem is required, existing dressings must be left in situ and covered and drainage tubes must be left in situ. Leaking orifices pose as a health hazard to all people coming into contact with the body.

15. If the child has any jewellery on check with the child’s parents/carers if they would like it to be removed before doing so. If they would like it to be removed give this to the parents/carers to retain. Refer to the section ‘Cultural and religious considerations’. If any jewellery is removed or remains on the child this should be fully documented.

16. The child’s body should be washed and dressed. This is for hygiene and aesthetic reasons, as a mark of respect and parents/carers should be invited to participate in the washing and dressing of their child, whilst supporting them to do this. Parents may request that the child is not washed for religious and cultural reasons.

17. If necessary clean the child’s mouth using a foam stick to remove any debris and secretions. Clean the child’s teeth using their own toothbrush and toothpaste. This is for hygienic and aesthetic reasons.

18. Brush the child’s hair and arrange it into the preferred style (if known) to help guide the funeral director for final presentation.

19. Parents should be asked if they have any specific preferences with regard to what they would like their child to be dressed in or if there is anything they would like to stay with their child such as a toy or a photograph.

20. A photograph, hand and foot prints and a lock of the child’s hair, or other appropriate mementoes, should be offered to the parents. If mementoes are taken these should be fully documented. These keepsakes are important in acting as a memory of the child for the family. Should the family initially decline the offer of such mementoes staff can, with the
parents consent, offer to keep these in the child’s file should the family change their mind at a later date.

21. All actions taken must be fully documented.

22. Dispose of equipment according to infection control principles. Remove gloves and aprons. Wash hands with soap and water following the six-stage Ayliffe technique (Appendix IV). This is required to minimise the risk of cross-infection and contamination.

23. A white sheet should be placed over the body with the head out and a hand should sit outside of the sheet so that family members can hold the child’s hand if they wish to.

24. The child’s body should be placed in a room which is cool but not too cold and well ventilated. Windows may need to be open and ensure radiators in the room are turned off. The body’s core temperature will take time to lower and therefore refrigeration within four hours of death is optimum. Guidelines suggest that the body should be placed in a room with the temperature being kept below 12°C, preferably between four and eight degrees. This however may not be tolerable for relatives who wish to be in the room for extended periods and there are now cold beds and blankets that are available which can offer effective cooling systems. Children’s hospices are using Flexmort, which is a manufacturing company that provides innovative mortuary systems for the cooling and storage of the deceased. Air-conditioning units may also be used to ensure the room is kept cool. The funeral director is also able to give support and advice about keeping the child’s body at home in the most appropriate environment.

25. The family should be given the opportunity to view the body if they wish to. They should be prepared for what they may see. Ensure the room is clean and tidy and that they are provided with a comfortable and private place to spend time with their child after death.

26. The body should be monitored as an ongoing process for any deterioration. Monitoring should be continued in consultation with the funeral director until the body is transferred to the coffin.

27. Viewing the body after three days after death is not recommended due to the natural deterioration of the body that takes place after this time.
Appendix 5 – Arranging a funeral – some helpful advice.

Choosing a Funeral Director

Choosing a funeral director can be difficult. Friends or relatives who have had to arrange a funeral may be able to suggest someone. If not, then you can contact The National Association of Funeral Directors (Available at: www.nafd.org.uk/funeral-advice/funeral-advice-home.aspx). They can provide you with the details of local funeral directors who are part of this professional association. Funeral directors will respect family wishes about the funeral and they will want to make this time as easy as possible for them.

When the family have made their choice, they will need to give the funeral director the certificate of burial or cremation that the Registrar gave them. The funeral director will organise for the child to be taken to the funeral director’s chapel of rest, if appropriate, or child can be transported to a hospice or hospital (see above).

Choosing the Type of Funeral

You can have the funeral at your local church, cemetery or crematorium. Special arrangements can be made with the child’s hospice if requested. If the funeral is at the cemetery or crematorium, families can have a minister of religion to lead the service, have a humanist ceremony or families can organise their own order of service. The funeral director will be able to put the family in touch with whomever the family need.

For a cremation families can choose what to do with the ashes. They can either be buried, or scattered in a cemetery or somewhere meaningful to the child/family. Some people choose to keep the ashes in their home or scatter them abroad. Families should speak to their funeral director for advice as they may need to pay a fee or seek permission in some situations. They can also advise you if they wish to choose a memorial.

Having Flowers or Donations

Many families now choose to have friends and relatives make a donation, instead of giving flowers in memory of the child who has died. The donations sometimes go to a charity or to the hospital or hospice where their child attended.

Unusual Situations affecting Funerals

Funerals may not be straightforward if there is a need for:

- A coroner’s inquiry
- A hospital post-mortem
- A burial abroad
## Equality Impact Assessment Proforma Initial Screening

<table>
<thead>
<tr>
<th>Section</th>
<th>Clinical: Clinical Guidelines</th>
<th>Officer responsible for the assessment</th>
</tr>
</thead>
<tbody>
<tr>
<td>Name of Procedural document to be assessed</td>
<td>Care of The Deceased Child – An Expected Death</td>
<td><strong>Date of Assessment</strong></td>
</tr>
<tr>
<td></td>
<td><strong>1st May 2013</strong></td>
<td><strong>Is this a new or existing procedural document?</strong></td>
</tr>
<tr>
<td></td>
<td><strong>N / E</strong></td>
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1. Briefly describe the aims, objectives and purpose of the procedural document.

   To inform and advise CFT staff working with deceased children and their families, in a home or community setting, where the death was expected.


   To guide staff through the appropriate care pathway to ensure safe, consistent and quality care in the incidence of a child’s expected death.

3. Who is intended to benefit from this procedural document, and in what way?

   All CFT staff for whom it is relevant: Children’s Community Nursing Team, Incl: Managers, Community nurses, Diana Nurses, Care staff, Home Care Team, Volunteers, carers. To provide information, procedure and guidance at the time of a child’s expected death.

4. What outcomes are wanted from this procedural document?

   To ensure a consistent approach from all CFT staff and to provide a practical guidance to assist them in their practice. To give Staff a tool to ensure that best practice and a caring, professional approach is maintained at all times, when working with children and their families at the time of a child’s expected death. To ensure all relevant training and staff competency levels are met, with regards to caring for a deceased child.

5. What factors/forces could contribute/detract from the outcomes?

   Contributing factors: Ensure Line Managers disseminate information regarding the policy and guidance, to formulate appropriate training, and arrange training provision. Detracting factors: Not carrying out the above – and Staff being unaware of the new policy and guidance. Lack of training/updates and monitoring.

6. Who are the main stakeholders in relation to the procedural document?

   Written and formulated by Ellie Retallack and Hayley Pocock – Children’s Community Nurses. 
   Line Manager – Caroline Amukusana.
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<table>
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<tbody>
<tr>
<td>8. Are there concerns that the procedural document <strong>could</strong> have a differential impact on <strong>RACIAL</strong> groups?</td>
<td><strong>Y</strong></td>
<td><strong>N</strong></td>
</tr>
<tr>
<td>What existing evidence (either presumed or otherwise) do you have for this?</td>
<td>Research carried out and information provided re. Differentials regarding a variety of cultures and religious groups.</td>
<td></td>
</tr>
<tr>
<td>9. Are there concerns that the procedural document <strong>could</strong> have a differential impact due to <strong>GENDER</strong></td>
<td><strong>Y</strong></td>
<td><strong>N</strong></td>
</tr>
<tr>
<td>What existing evidence (either presumed or otherwise) do you have for this?</td>
<td>Appendix provided at the end of the policy documentation.</td>
<td></td>
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<tr>
<td>10. Are there concerns that the policy <strong>could</strong> have a differential impact due to <strong>DISABILITY</strong>?</td>
<td><strong>Y</strong></td>
<td><strong>N</strong></td>
</tr>
<tr>
<td>What existing evidence (either presumed or otherwise) do you have for this?</td>
<td>Universal guidance – considers all genders.</td>
<td></td>
</tr>
<tr>
<td>11. Are there concerns that the policy <strong>could</strong> have a differential impact due to <strong>SEXUAL ORIENTATION</strong>?</td>
<td><strong>Y</strong></td>
<td><strong>N</strong></td>
</tr>
<tr>
<td>What existing evidence (either presumed or otherwise) do you have for this?</td>
<td>Universal and impartial guidance intended.</td>
<td></td>
</tr>
<tr>
<td>12. Are there concerns that the procedural document <strong>could</strong> have a differential impact due to their <strong>AGE</strong>?</td>
<td><strong>Y</strong></td>
<td><strong>N</strong></td>
</tr>
<tr>
<td>What existing evidence (either presumed or otherwise) do you have for this?</td>
<td>Universal and impartial guidance intended.</td>
<td></td>
</tr>
<tr>
<td>13. Are there concerns that the procedural document <strong>could</strong> have a differential impact due to their <strong>RELIGIOUS BELIEF</strong>?</td>
<td><strong>Y</strong></td>
<td><strong>N</strong></td>
</tr>
<tr>
<td>What existing evidence (either presumed or otherwise) do you have for this?</td>
<td>Therefore, research carried out and appendix completed to ensure a variety of religious groups and cultures have been included.</td>
<td></td>
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</tbody>
</table>

See above.
14. Are there concerns that the procedural document could have a differential impact due to their MARRIAGE OR CIVIL PARTNERSHIP STATUS? (This MUST be considered for employment policies).

| Y | N | Universal guidance intended. Reference is to ‘family’ and ‘families’ – not specific to married/unmarried partnerships. |

What existing evidence (either presumed or otherwise) do you have for this?

15. Are there concerns that the procedural document could have a differential impact due to GENDER REASSIGNMENT OR TRANSGENDER ISSUES?

| Y | N | Universal guidance intended. |

What existing evidence (either presumed or otherwise) do you have for this?

16. Are there concerns that the procedural document could have a differential impact due to PREGNANCY OR MATERNITY?

| Y | N | If staff/those involved at the time of a child’s death are pregnant, emotional health may be an issue. Document provides information on support to families and staff. |

What existing evidence (either presumed or otherwise) do you have for this?

17. How have the Core Human Rights Values of:
   - Fairness;
   - Respect;
   - Equality;
   - Dignity;
   - Autonomy

Been considered in the formulation of this procedural document/strategy

If they haven’t please reconsider the document and amend to incorporate these values.

Fairness: Document is intended to be universal and unbiased.
Equality: All echelons of society considered. Universal documentation.
Dignity: Safeguarding considered, - at the time of the child’s expected death and in the events following. Document includes consideration of family/carer feelings and emotional health at this difficult time. Practical guidance on how to care for the deceased child’s body, and cultural/religious groups considered.
Autonomy: Practical guidance included. Relevant training and ongoing monitoring required, and cited.
<table>
<thead>
<tr>
<th>18. Which of the Human Rights Articles does this document impact?</th>
<th>The right:</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>- To life;</td>
</tr>
<tr>
<td></td>
<td>- Not to be tortured or treated in an inhuman or degrading way;</td>
</tr>
<tr>
<td></td>
<td>- To be free from slavery or forced labour;</td>
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<td></td>
<td>- To liberty and security;</td>
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<td>- To a fair trial;</td>
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<td>- To no punishment without law;</td>
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<td>- To respect for home and family life, home and correspondence;</td>
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<td></td>
<td>- To freedom of thought, conscience and religion;</td>
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<td></td>
<td>- To freedom of expression;</td>
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<td>- To freedom of assembly and association;</td>
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<td>- To marry and found a family;</td>
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<td></td>
<td>- Not to be discriminated against in relation to the enjoyment of any of the rights contained in the European Convention;</td>
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<td></td>
<td>- To peaceful enjoyment of possessions and education;</td>
</tr>
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<td></td>
<td>- To free elections</td>
</tr>
<tr>
<td>Y</td>
<td>N</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>What existing evidence (either presumed or otherwise) do you have for this?</th>
<th>Articles highlighted are relevant for consideration within the documentation. Safeguarding, practical guidance, religious and cultural considerations, family wishes, funeral/burial choices, statutory, legal and local policies/procedures.</th>
</tr>
</thead>
<tbody>
<tr>
<td>How will you ensure that those responsible for implementing the Procedural document are aware of the Human Rights implications and equipped to deal with them?</td>
<td>Attach this Assessment and consider further training, or highlight/access existing human rights training (mandatory) that CFT offers.</td>
</tr>
<tr>
<td>19. Could the differential impact identified in 8 – 13 amounts to there being the potential for adverse impact in this procedural document?</td>
<td>Y</td>
</tr>
<tr>
<td></td>
<td>Universal and Impartial guidance intended. Draft versions sent out to Consultants, funeral directors, Cornwall coroner, Acute paediatricians, Community Paediatricians, Other Allied Professionals, Hospice, - for feedback and comments – nothing identified re. H R articles</td>
</tr>
<tr>
<td>20. Can this adverse impact be justified on the grounds of promoting equality of opportunity for one group? Or any other reason?</td>
<td>Y</td>
</tr>
<tr>
<td></td>
<td>No particular groups or variants highlighted in documentation, aside from Appendix which aims to include diversity of religion and cultures. It aims to offer staff a guidance on what a variety of the most prolific religious/cultural groups’ would prefer to happen at the time of a child’s expected death.</td>
</tr>
<tr>
<td>If Yes, describe why, and then proceed to a full EIA.</td>
<td></td>
</tr>
</tbody>
</table>
21. Should the procedural document proceed to a full equality impact assessment?  | Y | N  
If No, are there any minor further amendments that should take place?  | Nothing identified at this time.  
22. If a need for minor amendments is identified, what date were these completed and what actions were undertaken?  | Y | N  

Signed (completing officer)  | Ellie Retallack  | Date  | 01.05.13.  
Signed (Service Lead)  |  | Date  |  

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