# BCH Faith Matters Pathway

**Birmingham Children’s Hospital**

Child’s Name:  
DoB:  
NHS Number:  
Child’s Faith:  

Please consider and complete the relevant key points

**Part 1: Throughout the Palliative Care Journey:**

<table>
<thead>
<tr>
<th>Interpreter requirements:</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Visit from religious leader request:</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Breaking bad news support:</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Conducive visual space environment: Including images that might be offensive and what can be put in place to ensure comfort of the child</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Same gender care requirements:</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Modesty and clothing requests:</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Personal hygiene: Including keeping religious artefacts on the body (e.g. Sikh 5 K’s or Jewish Kippah)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Diet and food: including comments on fasting, vegetarian diets</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
</tr>
</tbody>
</table>

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| Part 1 Continued: Faith Matters Pathway |

| Belief about suffering, Death and Dying: Inoving views on the suffering of children and the afterlife |
| Religious and spiritual needs: In hospital, e.g. holy books and prayer (times, resources) |
| Visitors – family requests: |
| Life Support – families views: |
| Organ donation: Views on both receiving and donating |
| Post mortems – families views: |
| Care in the community - families wishes: |

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Faith Matters Pathway

Part 2: The Last 24 hours and Bereavement

Family Wishes:

Preferred place of death:

Inform: Which family members should be informed first (religious and cultural rules)

Rituals around the dying: End of life prayers, final blessings, last rites/rituals

Treatment of the body:

Rituals, washing, and treatment of the body: By whom, dos and don’ts

Rapid release: In light of religious needs for funeral to take place within a certain time frame.

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<table>
<thead>
<tr>
<th>Part 2 Continued: Faith Matters Pathway</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Organ and tissue donation:</strong></td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td><strong>Belief about Suffering, Death and Dying:</strong></td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td><strong>Large numbers of visitors:</strong></td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td><strong>Coroners:</strong></td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td><strong>Expressions of grief:</strong> <em>What expressions of grief can be expected (both culturally and religiously)</em></td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td><strong>Condolences:</strong> <em>What should be said (or avoided)</em></td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td><strong>Funeral:</strong> <em>Where is it likely to take place, who facilitates the service, what is likely to happen</em></td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td><strong>Burial or Cremation:</strong> <em>If either a religious requirement, comment here.</em></td>
</tr>
</tbody>
</table>
Part 2 Continued: Faith Matters Pathway

Belief about death and the afterlife:

Parents: How best to help parents from a faith perspective. What role does the bereaved parent play?

Grief and mourning: Any religious specific mourning rituals

Siblings: How to comfort a bereaved sibling, views of faith and suffering from a sibling perspective

Ongoing relationship with the deceased:

Counselling: Would counselling be appropriate? Faith specific?

How can a person not of this faith help?

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Organ and Tissue Donation

Patients and their families may want to know their choices about the donation of organs and tissues for the purpose of transplantation. The following information is set out to guide health care professionals when donation is raised for discussion.

Organ Donation

The kidneys, liver, heart, lungs, pancreas and small bowel can be donated after death for the purpose of transplantation. A child of any age can be considered as an organ donor after death, although there are both National and local guidelines which advise on the donation of organs from children younger than 6 months of age. Only a small number of children die in circumstances where they are able to donate their organs for transplantation, all being ventilated and cared for in an acute hospital trust and most dying as a result of a neurological injury and where death has been confirmed by Brain Stem Death testing. It is possible for a child to donate organs when death is certified by cardio-respiratory criteria (and are not Brain Stem Dead). This happens when there has been a medical decision to withdraw ventilation and extubate a child on grounds of futility and it is anticipated that death will occur imminently following this.

Children can not donate their organs for transplantation in the presence of an absolute contraindication. These are:

- Known or suspected nvCJD and other neurodegenerative diseases associated with infectious agents
- Known HIV disease (but not HIV infection alone)

In addition, it is highly likely that children with the following conditions will not be able to donate organs for transplantation. Further advice in these cases is essential;

- Disseminated Malignancy
- Melanoma
- Malignancy treated within past 3 years (except non-melanoma skin cancer)
- Known active Tuberculosis
- Untreated Bacterial Infection

It is essential that Health Care Professionals collaborate with the Specialist Teams for organ donation when assessing whether a child would be a suitable organ donor. An example of good local practice where collaboration works well for patients, families and the staff who care for them is an early notification or ‘Trigger’ tool which is in place in the Paediatric Intensive Care Unit at Birmingham Children’s Hospital. The tool ensures consistent and appropriate identification of children who may be able to be organ donors after
their death and ensures early involvement of a Specialist Nurse for organ
donation to assess suitability, plan and support an approach to the family and
then support the families’ decision regarding donation. This tool ensures an
approach regarding the choice of organ donation is always done ‘By the right
people’, ‘In the right way’ and ‘At the right time for the family’

Birmingham Children’s Hospital Paediatric Intensive Care Unit ‘Trigger’ Tool
for Organ Donation:

When there is a child ..... 

- With a severe neurological injury, requiring ventilatory support and
  Brain Stem Death is a possible diagnosis

  OR

- A child aged 6 months or above, requiring ventilator support and
  where there has been a decision to withdraw active treatment

Staff should contact the On Call Specialist Nurse for Organ Donation (SN-
OD) on 07659 137 821

Organ Donation is coordinated by a team of nurses known as Specialist
Nurse’s For Organ Donation. The on call nurse (Midlands Team) is available
for advice and support 24 hrs a day, 7 days a week, 365 days a year and can
be contacted via air pager 07659 137 821.

Tissue Donation

Eye tissue (corneas and sclera), heart tissue (aortic and pulmonary valve’s
and tissue patches), skin, bone and tendons are the tissues that can be
donated for transplantation. Tissues can be donated within 24 hrs of the
child’s death and can be donated from children who die in hospital or in the
community.
Tissue is normally retrieved in a mortuary; however, if the child dies in the
community setting local arrangements can be discussed.

A guidance of age range for tissue donation is;

- Eye donation – any age, although in cases of children under 3 years of
  age donation will only happen if there are recipients on the waiting list
- Heart valve donation – from 32 weeks gestation
- Skin and bone donation - over 9 stone
- Tendons – over 17 years
There are many more contraindications for the donation of tissue for transplantation. The main one’s are;

- History of chronic viral hepatitis or HIV disease
- CJD
- Untreated systemic infection
- CNS disorders of unknown aetiology
- Some cancer’s (although eye donation may be possible)
- Previous organ transplant

Tissue donation is coordinated by a Nurse from the National Blood Service (NBS) and is very different from organ donation. Although advice and support can always be sought from the on call Nurse, a referral will only be taken when the child has died, an approach has been made to the family and the family want to proceed with tissue donation. The tissue donation nurse does not attend the area where the referral is made. It is essential that Staff seek further information from the Tissue Nurse before any approach is made to a patient or their family.

Once the referral is made the family will be contacted by the Tissue Nurse who will talk through the tissue donation process and then take informed consent over the telephone. Final care arrangements (last offices) can continue as normal.

**The on Call Nurse for Tissue Services can be contacted via:**
Air Pager 0800 432 0559
Verifying and Certifying Death

When a child dies, they must be both verified to have died, and then certified as to the cause of their death.

Verifying a Child’s Death Involves:

Observing the child for at least 5 minutes to establish irreversible cardio respiratory arrest. This is established by a combination of:

- Confirming that there is no central pulse, eg, carotid or femoral pulse by palpation for at least one full minute
- Confirming that there are no heart sounds by auscultation for at least one full minute
- Confirming that there are no breath sounds heard by auscultation and no rise and fall of the chest for at least one full minute
- Confirming that pupils are fixed and dilated
- Confirming that there is no response to painful stimuli

In addition:

- Give adequate time to confirm all of the above, with longer assessment where appropriate. Extra care should be particularly taken when verifying death in neonates. Be thorough!
- Any additional related observations may be helpful to note, if, for example, livido reticularis or rigor mortis etc are evident at that time.
- Whilst verifying the child’s death, remember to also examine the child to confirm that there are no visible signs of concern.

Remember:

- This will be a very difficult time for the family. Think how you would wish yourself and a child of yours to be treated at such a time.
- All equipment (syringe drivers, nasogastric tubes etc) must remain in place until the child has been verified to have died and until no concerns have been raised and the case is confirmed not to need referring to the coroners.
- Explain to the parents what you need to do for legal purposes, before examining the child. It is respectful to ask their permission to do so. Their child should be treated with the utmost respect and dignity throughout the verification.
- Once you have verified that the child has died, confirm this sensitively to the family, and record your findings and time, along with the time the death was said to have occurred.
- If it is not a coroner’s case and you are able to complete the medical certificate of the cause of death, confirm with the parents how and when they will receive the certificate.
- All additional supportive information and materials required by the family at this stage in a non Coroners, non Rapid Response Enquiry Death, are outlined in the ‘When a Child Dies’ section of the toolkit.

You must discuss the case with the Child Death Review Paediatrician, and where appropriate, other agencies (Social Care,
Police etc) to determine whether any further action is required (Rapid Response Enquiry) or whether the death is considered to have been 'at the time, in the place, and in the manner' expected, with no concerns having been identified. You must do this even when the death was expected.

- See the section on ‘The Child Death Review Process’ or
- www.dcsf.org.uk.

If it is possible that this will be a Coroners Case, see below.

Where a Child’s Death is A Coroners Case:

Which deaths should be discussed with/reported to the coroner’s office?

A death would be reported to the Coroner if:

- The cause of death appears unknown
- The death occurred within 24 hours of admission to hospital, or when the child had been brought in dead
- The doctor attending the child did not see them within the last 14 days before death
- Death was related to injury, however remotely
- Death was not thought to be of natural cause
- Suspected suicide
- Deaths related to suspicious or criminal activity
- Deaths within 24 hours of surgery or anaesthetic, or anytime thereafter if the death is thought to be related to either.
- Deaths related to industrial disease or poisoning
- Deaths where there is a question of self neglect or neglect by others
- Death from hypothermia, food poisoning, alcoholism, or drug abuse.
- Deaths related to medical mishap if the relatives have criticised medical care, if related to the cause of death.
- If in doubt, the case should be discussed with the Coroners officer.

It is possible, after discussion with the Coroner’s Office, that the doctor will be able to complete the medical certificate of cause of death and that no further action will be required.

Where the case could possibly be a coroner’s one:

- The doctor should call the coroner’s office
- Inform the family. (They are unable to refuse the referral).
- The child’s body and surrounding objects should not be touched or moved
- All equipment (syringe driver, nasogastric tube etc) must stay in place (although the battery can be removed from the syringe driver).
- The coroner’s officers will then lead the ongoing investigation of the child’s death and the care of their body. They will discuss the case with staff and family and will arrange for the child’s body to be transported to hospital (by funeral directors) for a post mortem to be held. The decision re further investigation and issue of the medical certificate of cause of death will then lie with the coroner.
Certifying a Child’s Death

Once it has been confirmed that the medical certificate of cause of death can be completed, this should be done so as soon as possible to avoid unnecessary delay for the family. It is only after the medical certificate of cause of death has been issued that the funeral directors and family can proceed with the funeral arrangements.

The doctor who attended the child during the last 14 days of their life will be able to complete the death certificate. If the doctor did not attend the child in this period, then discussion with the coroner will be required first.

The medical certificate of cause of death is:

- Legal evidence of the cause of death.
- It also provides epidemiological data.

It is important to complete it as thoroughly as possible.

A specimen sample of a medical certificate of cause of death can be seen on the next page. Complete it as follows and indicated on the specimen:

1. Give the full name of the patient
2. Provide the date of death
3. Give the child’s age
4. Enter the place of death
5. Give the date that you last saw the patient alive.
6. Depending upon circumstances, circle 1, 2, 3 or 4 and a, b or c.
   - If a post mortem is being held by the coroner, then you will not be completing the death certificate. However, if the relatives consent to a post mortem, to gain further information about their child’s condition, (‘hospital post mortem’) then 1 or 2 will need to be ‘rung’. See also the section on ‘Post Mortems’ in the Toolkit.
7. The cause of death must be completed as thoroughly as possible. Do not give mode of death as a cause, eg, coma, cardiac arrest etc. An example may be:
   - 1(a) Intracerebral haemorrhage
   - 1(b) Cerebral metastases
   - 1(c) Osteosarcoma
8. Sign the form and print your name underneath your signature and add GMC number
9. ‘Residence’ can be completed as hospital or other place of work
10. Complete the counterfoil. On this section only, abbreviations are permissible.
11. The ‘Notice to Informants’ is completed and attached to the envelope containing the completed medical certificate of cause of death, and given to the relatives. It is important to explain to them, what has been written.

Note, this section must also be read with the section ‘Child Death Review Process’.

Up to date information can be sought at www.dh.gov.uk
What is a Post Mortem Examination?

A post mortem examination is an examination of a person’s body after death. An examination for a baby or child would be carried out by a consultant pathologist often at Birmingham Children’s Hospital or Birmingham Women’s Hospital if the child is a small baby or at the mortuary close to the Coroner’s Office. The purpose of the post mortem examination is to gain further information about the cause of death.

There are two types of post mortem examination:

**Consented** – This is an examination, which can be either requested by the child’s parents or by the Consultant caring for the child, in order to find more information about the child’s illness, when the cause of death is already known. This can only be done with the parents’ full permission and the parents have choices about the extent of the examination on what happens to any tissue samples.

**Coroner’s** – This is an examination ordered by HM Coroner, when the cause of death is unknown or the child’s death is unexpected, and as such becomes a legal requirement, so the parents consent is not required. Parents will have choices about what can happen to any tissues taken during this examination once the Coroner’s purposes are complete.

An examination after death can do the following:

- Help to confirm the cause of death
- Show other diseases or conditions that may have been present but may not have been obvious at the time
- Assess the effectiveness of treatment and medication given, such as radiotherapy and chemotherapy for cancer
- In some cases it may help with the planning of future pregnancies
- Help to answer questions about potential health problems that may run in the family
- Help to answer questions that the parents may have in the future

By law the **Coroner** can order a post mortem examination to be undertaken. There are 3 main reasons why the Coroner may do this. They are:

- If the child’s death was sudden and unexpected
- The doctor caring for the child is unable to provide a cause death
The child’s death was the result of an accident or unusual circumstance (including deaths following a medical procedure such as surgery)

Consent for a Post Mortem Examination

Consent for a consented post mortem examination can only be taken by professionals who have had specific training in taking consent for the procedure. The Laws which apply to the treatment of a child after death are contained within the Human Tissues Act 2004. The consent forms for a Consented Post Mortem Examination are specific forms and families must be fully informed about the nature of the post mortem examination and give full consent about how tissue samples and biopsies are treated after the examination. The Pathologist performing the examination must also be involved in the consent procedure. The consent is recorded on specific consent forms and parents must be given written information about the examination to fully explain the procedure.

Coroner’s Post Mortem Examination

The Coroner may order a post mortem examination without the parents’ consent. The process of informing the parents about the examination is undertaken by the Coroner’s Officer who has specific training informing families about what will happen. A Coroner’s Post Mortem examination may happen at a Hospital or at a mortuary close to the Coroner’s Offices. Once the Coroner has completed his investigation the parents can chose what happens to any tissue samples taken during the examination.

How do Parents Get the Results of the Examination?

Consented Post Mortems

If the parents have consented to an examination, then they will be offered an appointment with the Consultant who was in charge of the child’s care, approximately six to eight weeks after the examination. The report will be available for this meeting, and the findings and any implications will be discussed with the parents and family.

Coroner’s Post Mortems

If the Coroner has ordered the examination, the results will be given to the family via the Coroner’s office. The parents will also be offered an appointment to discuss the findings with their Consultant as well. However the parents should be aware that the Coroner’s permission will be required for this meeting, and he may not allow the meeting to take place until after the inquest is complete.
Information Leaflet for parents, families and carers

When a child dies at Birmingham Children’s Hospital

Revised April 2009
### Contents Page

<table>
<thead>
<tr>
<th>Topic</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>When your child dies at BCH</td>
<td>1</td>
</tr>
<tr>
<td>Hospital Bereavement Appointment</td>
<td>2</td>
</tr>
<tr>
<td>The Rainbow Suite</td>
<td>2</td>
</tr>
<tr>
<td>Taking your child from the hospital</td>
<td>2</td>
</tr>
<tr>
<td>Obtaining a medical certificate of death</td>
<td>3</td>
</tr>
<tr>
<td>Organ donation</td>
<td>3</td>
</tr>
<tr>
<td>The need for a post mortem</td>
<td>3</td>
</tr>
<tr>
<td>When the Coroner is involved</td>
<td>4</td>
</tr>
<tr>
<td>Registration of the death</td>
<td>4</td>
</tr>
<tr>
<td>Arranging a funeral</td>
<td>6</td>
</tr>
<tr>
<td>Choosing a Funeral Director</td>
<td>7</td>
</tr>
<tr>
<td>Cremation</td>
<td>8</td>
</tr>
<tr>
<td>Burial</td>
<td>9</td>
</tr>
<tr>
<td>The Ceremony</td>
<td>9</td>
</tr>
<tr>
<td>Burial/Cremation out of England and Wales</td>
<td>9</td>
</tr>
<tr>
<td>Your grief: How you might feel</td>
<td>10</td>
</tr>
<tr>
<td>If there are other children in your family</td>
<td>11</td>
</tr>
<tr>
<td>The hospital Book of Remembrance</td>
<td>11</td>
</tr>
<tr>
<td>Opportunities for Sharing</td>
<td>12</td>
</tr>
<tr>
<td>Further Support</td>
<td>12</td>
</tr>
<tr>
<td>Support In The Community</td>
<td>13</td>
</tr>
<tr>
<td>Space for Questions</td>
<td>19</td>
</tr>
<tr>
<td>Useful Numbers at BCH</td>
<td></td>
</tr>
</tbody>
</table>

When a child dies at Birmingham Children’s Hospital
We would like to offer you our deepest sympathy at this difficult time.

We hope that this leaflet will help you with the practical arrangements.

Please ask us if you need any help. There are many members of staff who will be able to help you. The nursing staff and Bereavement Care Services Team will be pleased to talk to you about the choices you can make.
When your child dies at Birmingham Children’s Hospital

When your child dies, we want to help you do whatever is right for you and your family.

You and your family may like to have a short blessing or ceremony for your child. The hospital Chaplain and the Chaplaincy Team can arrange this for you. They can also call your own religious leader for you.

The hospital has many trained staff to help you at this time. The Doctors, Nurses, the Bereavement Care Services Team or the specialist liaison staff will be pleased to talk with you. You will be able to be with your child and spend time together as a family. Special momentos, toys and favourite things can stay with your child all the time. Please feel free to talk to the nursing staff about this.

We can make up a card of remembrance for you, if that is what you would like, with a lock of hair, handprint, footprint and photograph of your child. Please ask if there is anything else you would like us to include.

You can take this card with you when you leave the hospital or the Bereavement Care Services Team will make sure you receive it later on.
need to complete some forms first and then you will be given a letter of consent to take home with you. Please ask us if you would like to know more about taking your child home.

**Obtaining a medical certificate of death**

When your child dies, the hospital Doctor who looked after your child will issue a medical certificate stating the cause of death. The certificate is needed to register your child’s death. There may be a delay if the Coroner has to be involved.

**Organ donation**

The possibility of organ donation may or may not be something you have already thought about. Nursing and other medical staff will usually discuss this with you if it is appropriate.

**The need for a post mortem**

A doctor may ask for your permission to do a post mortem examination at the hospital to try and find out more about why your child has died. A hospital post mortem should not delay funeral arrangements. If a hospital post mortem is requested, senior medical staff will explain what will happen and give you a chance to ask questions. You will also be given an information leaflet that will help you to make a decision. If you agree you will be asked to sign a consent form.
When the Coroner is involved

In certain circumstances the law states that the Coroner needs to be notified to help find out why your child has died, you will be kept fully informed. When this is necessary the Coroner can order a post mortem.

The Coroner may decide to hold a full or fast track inquest

Registration of the death

If the Coroner is not involved you must register your child's death within 5 working days. You may either register the death in Birmingham, where you will be issued with the necessary paperwork immediately, or you may register at your own local Register Office by Declaration. This will mean the transfer of your child's details from your local Register Office to Birmingham. The paperwork will be sent to you through the post. This will obviously take a few days longer. It is important to think about this when you are making your child's funeral arrangements.

Parents are strongly advised to register their child's death if at all possible, either in person or by Declaration as described above in order to make sure the information on their child's death certificate is correct. However, if it is not possible for you to register the death, for example if you live some distance from Birmingham, then the death can be registered by:
• A relative

• A person designated as “occupier” from the Birmingham Children's Hospital, namely the Bereavement Services Co-ordinator or Family Liaison Sister from PICU.

The Register Office needs the following information:

• Medical certificate of cause of death given to you by the hospital Doctor

• “Notice to informants” issued with the medical certificate of cause of death

• Medical Card (if available)

• The child's full name, home address, date and place of birth.

• Parents full names, home addresses and occupations

• A list of benefits the child was receiving e.g. Disability Living Allowance

The Registrar will issue the necessary certificate for burial or cremation. This is called the Green Form. You will need to give this to the Funeral Director as soon as possible so that the funeral can take place.

You can buy a copy of the death certificate from the Registrar for a fee. Further copies can be purchased to meet the needs of each family's circumstances.
Generally you must register the death and obtain a certificate for burial or cremation before you can arrange the funeral. The emergency service will allow you to arrange a burial when the office is closed, the death will still need to be registered as soon as possible.

If you haven't registered your baby's birth you can do this at the same time. This can be done in Birmingham, even if your child was not born here. If you and your partner are not married, you both need to be present at the registration of the birth for both names to be on the birth certificate.

- You must register the birth within 6 weeks of the date of birth
- You must register the death within 5 days of the date of death

Register Office, Holliday Wharf, Holliday Street, Birmingham B1 1TJ, England, United Kingdom Telephone: 0121 675 1004 (direct line)

Directions to the Register Office are included on a separate sheet inside this information leaflet.

**Arranging a funeral**

The following points may help you to decide what arrangements you would like to make for your child. There is no hurry to make arrangements unless there are special religious or cultural reasons.
• The funeral is a very special occasion, so it is important for you to have the funeral that you want for your child. You may like to discuss your needs with your family, friends and your funeral director.

• Our hospital Chaplains are available for advice with funeral arrangements and have conducted funerals for some families in the past.

• You may be concerned about the funeral costs. If you are receiving any benefits check with your local Jobcentre Plus Office to see if you are entitled to any help with funeral expenses.

• You may be able to claim the funeral expenses by completing the form SF200 which is available from the hospital, Funeral Director or local Jobcentre Plus Office.

• Most funeral services offer families a Funeral Plan to help cover the basic costs. This will depend on your family circumstances. For further information about Funeral Plans please ask when you first meet with your chosen Funeral Director.

Choosing a Funeral Director

It is possible to arrange a funeral yourself, or you can ask a Funeral Director to take care of everything on your behalf. It may be a good idea to ask a friend to contact a few funeral directors so that you have a choice. There can be some differences in the services provided and the costs involved.
Some do not charge for their services for the funerals of children, but will charge you for fees they pay out on your behalf.

The Funeral Director will need the Green Form given to you by the Registrar when your child’s death is registered or the forms issued by the Coroner. They will contact the hospital and take your child back to their own Chapel of Rest.

Your Funeral Director will give you a written estimate of the costs of the funeral. They will also be able to tell you what services they provide.

If you have any special requests or concerns, don’t be afraid to ask your Funeral Director.

Cremation

If you want your child to be cremated you will need a completed set of forms signed by the hospital Doctors, so please let the hospital know. These will be collected by the Funeral Director when they collect your child. These are called “Cremation Forms.”

A service can be arranged at a Crematorium or, if you prefer, you can have a service at another place of worship first.

There are many ways you can have a memorial of your child at the Crematorium. Ask your Funeral Director about caskets if you wish to keep the ashes. You can also bury or scatter the ashes in a place that is special for you.
Burial

There are several choices about where your child can be buried. You may want to discuss this with your Funeral Director. You should ask your religious leader if you want your child to be buried in a churchyard or you can contact any local authority cemetery of your choice.

The Ceremony

You can hold a ceremony anywhere you choose, it does not have to be religious and can include favourite songs, hymns and readings. This can be held at home if you wish. Ask your Funeral Director or religious leader for guidance.

Burial/Cremation out of England and Wales

If you want your child to be buried or cremated out of England and Wales (this includes Scotland and Ireland). The Funeral Director will help you to arrange this. If you have decided to arrange this yourself the hospital will be available to help you.

Once you have registered your child’s death you will need to purchase a copy of the Death Certificate and take it to the Coroner. You will then need to get an “Out of England” Certificate from the Coroner, who will give you more advice. There is no charge for the “Out of England” Certificate.
A “Free from Infection” letter will also be needed. The hospital doctor will give you this. If your child is not free from infection, there may be difficulties in being allowed out of the country. Your Funeral Director or hospital staff will be able to give you more information.

**Your grief: How you might feel**

No one will be able to tell you exactly how you may feel, as everyone feels and acts differently. There is no right or wrong way to grieve. You may experience a whole range of feelings including numbness, disbelief, anger, guilt, emptiness, relief. Any of these feelings are all very normal.

There are many ways to cope. You might want to:

- Use your own family and friends for support
- Talk to previously bereaved parents
- Find religious or spiritual support
- Contact support groups or charities such as the Child Death Helpline, Child Bereavement Charity and Winston’s Wish
- Talk to a trained counsellor for bereavement services
- Contact specialised hospital staff, doctors or nursing staff
If there are other children in your family

Children need to grieve as well; This can be difficult for parents and families as the natural instinct is to protect them from pain. But children need an explanation of what has and is happening. If no explanation is given they may over hear information and imagine things far worse than reality.
To cry with your child is normal and natural and it is natural they will be upset too.
Children also need to have the chance to be involved in what is happening. You may want to give them the chance of visiting their brother or sister who has died.
Many children, if prepared, find this helpful in accepting the situation. Talking with them about the funeral and also giving them the choice to be involved in some way often helps a great deal. Details of where to obtain further support and information are included on a separate sheet inside this leaflet.

The hospital Book of Remembrance

The hospital has a non-religious Book of Remembrance where your child’s details can be inscribed. You will be sent a form 2 months after the loss of your child. If you would like us to include your child’s details, please send the form back to the hospital Chaplain, who will arrange for the entry to be made. It usually takes a few months for the inscription to be completed. There is no charge for this service, however donations are welcome.

If you plan to visit the hospital to view the book, please let the Chaplaincy Department know beforehand on 0121 333 8526 so that the book can be opened at the correct page for you.
Opportunities for Sharing

At Birmingham Children's Hospital we aim to give you different opportunities to meet with staff and other bereaved families throughout the year. The Chaplaincy Team will write to you within two weeks of the loss of your child with a small booklet.

If you have other children the Chaplaincy Team and wards have some booklets to help explain death to children of different ages. Please contact them or Bereavement Care Services to discuss your needs.

Some support events are held every year and you will be contacted. These events include the Annual Memorial Service and the Riverside walk and picnic.

Further Support

The Bereavement Care Services Team at the hospital is available if you need advice and support. They will contact you at the earliest opportunity following your child’s death and they will also be able to put you in touch with other external support. Bereavement Care Services Team will also be able to put you in touch with other external support agencies.

Tel: 0121 333 8889 (if no one is available to take your call please leave a message and we will contact you as soon as possible).

You will be offered the chance to meet with your child’s Doctor, usually after about 6 weeks to discuss the medical care your child received at Birmingham Children's Hospital.
Support at a later stage is also offered by our: Bereavement Counsellor on 0121 333 8057 or The Chaplaincy Team on 0121 333 8526
Further information and signposting to other sources of support is available from the Child and Family Information Centre. This is on the Ground Floor of the hospital near the Main Reception desk.

Support in the Community

Family Support Groups and Other Agencies

Acorns Children’s Hospice
8a Wake Green Road
Moseley
Birmingham B13 9EZ
Telephone: 0121 248 4800
Website: www.acorns.org.uk

BLISS – The Premature Baby Society
9 Holyrood Street,
London Bridge
London SE1 2EL
Telephone: 0870 7700 337
Parent Support Helpline: FREEPHONE 0500 618140
Email: information@bliss.org.uk
Website: www.bliss.org.uk
The Child Bereavement Trust
Aston House
West Wycombe
High Wycombe
Bucks HP14 3AG
Telephone: 01494 446 648
Email: enquiries@childbereavement.org.uk
Website: www.childbereavement.org.uk

The Child Death Helpline
Telephone: FREEPHONE 0800 282 986
Website: www.childdeathhelpline.org/

Compassionate Friends
53 North Street
Bristol BS3 1EN
Telephone: 08451 203 785
Helpline: 08451 232 304
Email: info@tcf.org.uk
Website: www.tcf.org.uk

Contact a Family - National
Freephone Helpline: 0808 808 3555
Email: helpline@cafamily.org.uk

Contact a Family – UK Office
209-211 City Road
London EC1V 1JN
Telephone: 020 7508 8700
Email: info@cafamily.org.uk
Website: www.cafamily.org.uk
Contact a Family – West Midlands
Prospect Hall
12 College Walk
Selby Oak
Birmingham B29 6LE
Telephone: 0121 415 4624
Email: westmidoffice@cafamily.org.uk
Website: www.cafamily.org.uk/wmids

CRUSE Bereavement Care – Birmingham Office
3rd Floor – King Edward Building
205 Corporation Street
Birmingham B4 6SE
Telephone: 0121 687 8010
Email: crusebirmingham@aol.com

CRUSE Bereavement Care – UK Office
Cruse House
126 Sheen Road
Richmond
Surrey TW9 1UR
Telephone: 0870 167 1677
Email: helpline@cruse.org.uk

FSID – The Foundation for the Study of Infant Deaths
11 Belgrave Road
London SW1V 8B
Telephone: 0207 8023200
Helpline: 0207 233 2090
Email: fsid@sids.org.uk
Website: www.sids.org.uk/fsid/contactus
Inquest
89-93 Fonthill Road
London N4 3JH
Telephone: 020 7263 1111
Email: inquest@inquest.org.uk
Website: www.inquest.org.uk

Jewish Bereavement Counselling Service
8-10 Forty Avenue
Wembley HA9 8JW
Telephone: 020 8385 1855
Email: jbs@jvisit.org.uk
Website: www.jvisit.org.uk

Muslim Bereavement Service
See Item 3 – Funeral Directors (this is a practical service and not a helpline)

National Bereavement Helpline
Office No.3D
3 Bear Street
Barnstaple
North Devon EX32 7DB
Telephone: 0845 226 7227
Email: info@natbp.org.uk
Website: www.natbp.org.uk

Relate – Birmingham Office
111 Bishopsgate Street
Birmingham B15 1ET
Telephone: 0121 643 1638
Relate – Central Office
Herbert Gray College
Little Church Street
Rugby
Warwickshire CV21 3AP
Telephone: 01926 403340
Email: enquiries@relate.org.uk
Website: www.relate.org.uk

RoadPeace – National Charity for Road Traffic Victims
94B Shakespeare Business Centre
245a Cold Harbour Lane
Brixton
London SW9 8RR
Helpline: 0845 4500 355
Email: info@roadpeace.org
Website: www.roadpeace.org

Samaritans – Birmingham Office
13 Bow Street
Birmingham B1 1DW
Telephone: 0121 666 6644
Website: www.birminghamssamaritans.org.uk

Samaritans – UK Office
Telephone: 0845 790 9090
Email: Jo@samaritans.org
Website: www.samaritans.org.uk
SANDS – Stillbirth and Neonatal Death Society
28 Portland Place
London W1N 1LY
Helpline: 0207 436 5881
Email: helpline@uk-sands.org
Website: www.uk-sands.org

Sudden Death Association
Eldan House
The Street
Eversley
Hook
Hants RG27 0PJ
Telephone 01189 733 939
Website: www.patient.co.uk

Sunrise Child Bereavement Centre – West Midlands
43a Calthorpe Road
Edgbaston
Birmingham B15 1TS
Telephone: 0121 454 1705
Website: www.edwardstrust.org.uk

Walsall Bereavement Support Service
Market House
13 Lower Hall Lane
Walsall
West Midlands WS1 1LR
Telephone: 01922 724 841
Website: www.wbss.org.uk
Winston's Wish
Westmoreland House
80-86 Bath House
Cheltenham
Gloucester GL53 7JT
Telephone: 08452 030405
Email: info@winstonswish.org.uk
Website: www.winstonswish.org.uk

Funeral Directors

Email: info@uk-funerals.co.uk
Website: www.uk-funeral-directors/westmidlands

Please use this space to write down any notes or questions you might have

please turn over the page
Useful Numbers at Birmingham Children's Hospital

Ward Tel No..............................................................

Birmingham Children's Hospital: 0121 333 9999 (switchboard)
Bereavement Care Services Team: 0121 333 8899/8890
Bereavement Counsellor: 0121 333 8057
Chaplaincy Department: 0121 333 8526
Child and Family Information Centre: 0121 333 8505
Patient Advice and Liaison Service (PALS): 0121 333 8403/8611
Social Work Department: 0121 333 8900

Other Useful Numbers

Birmingham Coroners Office: 0121 303 3920/3228
Birmingham Register Office: 0121 675 1004 (Reception Desk)
Child Death Freephone Helpline: 0800 282 986

This leaflet has been produced by the Bereavement Interest Group at Birmingham Children's Hospital.

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Website: www.bch.nhs.uk
When a Child Dies At Home

This document aims to provide useful information and advice to help you at the very difficult time of the death of your child, when this takes place at home, during the early stages of your bereavement. If you are unclear about any information please ask your named nurse.

Practical Necessities: What to Do First

Following the death of your child at home there are certain things that need to be done. It is important to feel that you have a choice in what happens next. You may wish to be on your own as a family, call upon friends and family or call professionals to offer support.

Who to Call

When your child dies following planned terminal care at home, there should be no need for the G.P or lead doctor in your child’s care to be contacted immediately by yourselves. You may feel that you would like to spend some time together on your own as a family first. However (due to the Child Death Review Process) the nursing team will need to be informed by telephone when your child dies. They will not necessarily visit immediately. They will let your child’s GP or lead doctor know of your child’s death.

The nurse on call will then be able to visit when you as a family feel ready. One or two nurses may come to your house; they may not live in close proximity to your address but be reassured they will get to you as soon as they possibly can.

When the nurses arrive they will do as much or little as you wish. This may include arranging when your child’s GP or lead doctor will visit and contacting your chosen funeral directors.

Your child’s G.P or lead doctor will need to visit your home to verify your child’s death and to arrange for your child’s death to be certified, where this follows a planned episode of terminal care at home.

Funeral Directors

You will need to contact a funeral director and you can ask your nurse to help you with this.

You may wish to keep your child at home after they have died, for a short period of time or until the funeral. Your child’s nurse and the funeral directors can give you support and advice about how to keep your child at home in the most appropriate environment.

You need to consider a few things when keeping your child at home. Your child’s body will begin to deteriorate. Therefore if you are keeping your child at
home for more than a few hours you will need to keep the room as cool as possible by opening windows and turning off radiators. The section below gives more detailed advice about caring for your child’s body at home and your child’s nurse and funeral directors will be able to give you further help.

If you wish to keep your child at home for more than a couple of days your child may need to be embalmed. Your chosen funeral directors will be able to inform you of the advisability of this. The embalming usually takes a few hours. The funeral directors will come to collect your child from home and return them following the procedure.

**Information on Caring for Your Child’s Body at Home if Your Child Has Died in Hospital or Hospice**

If you wish, it is your right as a parent to take your child’s body home unless your child has an infectious disease, or the death has been reported to the coroner. We hope that this information will help you at this sad and difficult time with some of the practical matters.

Children of any age can be taken home. You can decide whether this is in your own car or with assistance from your chosen funeral director. It may be advisable to have relatives or friends with you if you are wishing to undertake this in your own vehicle. If you use your own transport you will be provided with a letter from the hospital or hospice which will explain the situation to the relevant authorities in the event of a motor vehicle accident during the journey.

On reaching home please ensure your child is kept in a cool, well ventilated room. It is normal for your child’s skin to become cold, pale or discoloured. Think about which room you would like your child to be in. As friends and relatives may frequently be in and out of the house in the days following the death, it may be advisable to not place the child in the main living area of the house. Prepare a bed in the chosen room and keep bedclothes to a minimum. It may be helpful to place a waterproof cover over the mattress.

The room needs to be kept cool therefore we would advise you to keep the windows open, turn off any heating in the room and close the curtains if the sun is shining in. During hot weather it may be possible to hire a portable cooling system from the undertaker; this may help to delay the changes that occur. Air fresheners and or aromatherapy burners /candles may help. Small amounts of clinical waste may be disposed of by wrapping up within normal household waste.

During hot weather it may be best to think about letting your child’s body go to the Chapel of Rest. Again you can discuss this with your funeral director.

Embalming your child is sometimes possible. This process is performed by the funeral director and may delay the breakdown of the body. We would advise you to telephone your chosen funeral director who will be able to help with any further questions and assist with the funeral arrangements.
If your child is being cremated the cremation forms will need to be completed before embalming can take place.

If you are going home with your child, your GP and Health Visitor/Community Nurse will be notified by the hospital or the hospice so that they can be there to support you.

**Registering the Death**

Once you have obtained the Medical Certificate (stating the cause of death) the death must be registered. The death can be registered at the local office of Registration of Births, Marriages and Deaths in the district where the death occurred. This needs to be done within five working days of the death.

You will usually need to ring the Register office to make an appointment to register the death. Appointments last approximately 30 minutes. People who can register a death which has occurred at home are:

- A relative of the deceased.
- Someone who was present when your child died.
- The person making the arrangements with the funeral directors.

**Local Register Office Contact Details:**

**What Should You Take To The Register Office?**

- The Medical Certificate of the cause of death.
- Your child’s NHS number which is on his/her medical card.
- Any forms given to you if your child has been referred to the coroner.
- Your child’s birth certificate if the birth has been registered. (The date and place of birth are required if your child’s birth has not been registered).
- Money to obtain copies of Death Certificate which may be required for insurance policies or financial matters.
What Will The Registrar Give You?

- A certificate for burial or cremation. This form is currently a green form. You will need to give this to the funeral directors before the final arrangements for your child’s funeral can be made. An additional certificate is needed if you are planning to have your child cremated. The funeral director will arrange to get this form for cremation from the doctor.
- Form BD8 - notification of the registry of the death. You will need this form if you are applying to the DSS for a funeral grant.

The registration and issue of these two forms is free. A certified copy of the Death Certificate is also available for a small charge. This is essential if arranging a funeral abroad or if your child had any savings accounts.

(If the coroner has been involved you will have been given an order for Burial or a Certificate for Cremation.) The Funeral Director will need whichever form you are given so that the funeral can take place.

Financial Assistance

Some funeral directors offer “free” services for children's funerals; however there may be some costs if you have special requirements. If you receive certain benefits (for example, Income Support, Housing benefit and others) you can apply to the Social Fund for help to pay for the costs of the funeral. However, please be aware that if funds are allocated they may not cover all of your requirements.

You will need to complete an Application Form SF200. This is available from your social services office, post office and most funeral directors.

We understand and acknowledge that this is a very difficult and emotional time for you and your family and wish as a team to offer our sincere condolences for your loss.
Consent Letter to Take a Child’s Body Home from BCH

Letter of Consent to Take a Child’s Body Home by Car

Date:

To whom it may concern,

Name: ________________________________________________

Registration No: ______________________________________

Address: ____________________________________________

_____________________________________________________

This family is taking their child home from hospital.

The child died in the Birmingham Children’s Hospital and the family wish to have their child at home prior to the funeral.

The child died of natural causes and the doctor/s is/are happy to issue the death certificate.
Name of doctor/s:

If you need confirmation of these details please contact the hospital. However, please note no additional information will be given without permission of the parents.

Yours faithfully,

Nurse in charge of ward:

Print name: _________________________________________

Telephone number of ward:
**Check List for Notification of a Child’s Death**

The check list has been designed to act as an aide-memoire for staff when considering who should be contacted following the death of a child. In many cases there can be a vast number of professionals from all agencies involved in the care of a child. The check list can be systematically worked through to avoid anyone involved in the child’s care being missed and therefore left in the difficult position of contacting the family unaware that the child had died.

**It is important to ascertain which people the family may wish to contact themselves to prevent any breach of confidentiality.**

**Death Notification**
*Please obtain parental consent prior* to informing others and ascertain if the family wish to contact anyone themselves.

Name ........................................................................................................Date of Death

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<th>Name</th>
<th>Phone</th>
<th>Signature</th>
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<td>Child Death Review</td>
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<td>Pre-school Education</td>
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<td><strong>Other Teams</strong></td>
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<td>Occupational Therapy</td>
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<td>Social Worker</td>
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<td>Learning Disability Team</td>
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<td>Child Development Team</td>
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<td>Medical Aides/Equipment Stores</td>
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<td>Enteral Feeding Service</td>
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<td>Incontinence Services</td>
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<td><strong>Hospital</strong></td>
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</table>
Consultant
Hospital Wards
Pharmacy/Chemist
Dietician
Hospital School/Home Tuition

**Miscellaneous - to be considered**

Hospice
Respite Centre
Short Break Services
Crossroads
SCOPE
SENSE
Family Fund

This list is not exhaustive and can be added to manually if necessary
Memory Boxes

“Grief is not about forgetting the person who has died but finding ways to remember them and take their memory forward. However, it can be difficult for children to hold on to their memories.” [www.mcmillan.org.uk](http://www.mcmillan.org.uk)

Memories are very important as people travel through the grieving process and as time passes some parents, young people, or children find it harder to remember. Therefore the use of a memory box can be helpful in capturing special memories.

A memory box is a special container which can be used to hold special memories belonging to a loved one. Children can be involved in making their own memory box depending on their age.

The memory box can be as simple or elaborate as you wish. It can be made from a shoebox, biscuit tin or gift box.

Winston’s Wish ([www.winstonswish.org.uk](http://www.winstonswish.org.uk)) or The Child Bereavement Charity ([www.childbereavement.org.uk](http://www.childbereavement.org.uk)) or other organisations online do make specially made memory boxes if you prefer.

When giving a memory box from your service to a parent, be mindful of the context in which it is given and perceived by the parent. It is always helpful to explain the purpose of the box before it is given.

What goes Into a Memory Box?

The contents really are of personal choice. Anything that is important to you or your child or your brother or sister can go into the box. These are just a few suggestions of what other people have put in their box;

- A photo of your child or brother or sister can be put on the lid.
- Disposable camera
- Letters
- Personal notelets i.e. “I love you because.”
- Perfume/aftershave.
- Items of jewellery.
- Items of clothing.
- Postcards from holidays.
- CD of music.
- Shells, cones, feathers.
- Cards
- Recording of you singing or talking together.
  - Pair of scissors for a lock of hair.
  - Handprints or footprints.
  - Special toy.

This list gives ideas of what may be considered helpful inside a memory box. This list is not exhaustive and must be kept personal to each individual.
The Child Death Review Process

When a child dies there are statutory obligations other than those of informing the Registrar, to also inform of the child’s death to the Child Death Review Officer, and to consider whether the death was expected or not in all aspects. This applies even when the death is in a child with an underlying life limiting or life threatening condition. Chapter 7 of Working Together to Safeguard Children sets out these procedures to be followed when a child dies. The guidelines apply to all child deaths and there are two interrelated processes for reviewing child deaths that encompass all child deaths:

A rapid response by a group of key professionals who come together for the purpose of enquiring into and evaluating each unexpected death of a child and

An overview of all child deaths (under 18 years) in the local safeguarding children board (LSCB) area(s), undertaken by a panel.

The first process around Rapid Response is unlikely to need to be actioned in the death of a child receiving palliative care where their death is in the manner, time and place expected. However there are times when the death can be unexpected in time or manner and discussion will be needed to determine whether any further action is required.

Child Death Overview Panels (CDOP’s) are responsible for reviewing information on all child deaths, whether expected or not and are accountable to the LSCB Chair. Hence expected palliative care deaths will be reviewed at the CDOP. CDOP’s may serve more than one LSCB. Child Death Review Processes became mandatory in April 2008, though LSCBs have been able to implement these functions since April 2006.

It is the responsibility of the team caring for a child who dies an expected death whilst receiving palliative care to notify the child's death and comply with the Child Death Review Process, as is also necessary with those dying unexpectedly but with an underlying palliative care need and all other child deaths.

A Department for Education Working together Flow Chart outlining the approach to decision making re action on the death of a child, follows in the Toolkit.

It is anticipated that the Rapid Response Process will not be begun or will be stopped immediately where discussion with the lead paediatrician for the Child Death Review confirms that the death was expected in time, manner and place.

However, it is important for families to realise that if the family make a 999 ambulance call and the child is found to have died, then the Ambulance Staff will contact the Police as their statutory obligation and a Rapid Response enquiry will need to be started. It is therefore important that staff are available out of hours to be contacted to discuss and clarify that the death was
expected and to enable the Rapid Response process to be stopped where appropriate.

Where a death is considered imminent, it is wise to inform the local Paediatrician for the Child Death Review Process and/or the Coroner to support the smooth and sensitive handling of the death for the family.

Child-death information national templates for local Safeguarding Children's Boards (LSCBs)

Templates for completion of the written notification after verbal discussion in line with local and national guidelines are available on the Department for Education’s website as below:


The relevant forms, available via the above link, require completion in the case of a child/young person (under 18 years) who dies of a life limiting condition:

Form A Notification of Child Death (automatic completion by lead professional following the death of the child, by the next working day)
Form B Agency Report (requested by LSGB at a later date)
Form B3 Also completed where the death is in a child with a known Life Limiting Condition

In addition where the death was in a neonate, then neonatal forms require completion (Form B2).

Working Together to Safeguard Children can be viewed at:


where Chapter 7 relates to the Child Death Review Process
Flow chart 6: Interface between the child death and serious case review processes

- **Child Dies**
  - **Is the death unexpected?**
    - **YES**
      - Collection of information on child
      - **Information received by overview panel**
      - **Identification of lessons learned**
      - Dissemination of lessons learned
      - Follow Chapter 8 guidance
    - **NO**
      - Case discussion following final results of postmortem
  - **NO**
    - Case discussion following preliminary results of postmortem
    - Follow Chapter 8 guidance

- **Are the criteria met for SCR?**
  - **YES**
    - Follow Chapter 8 guidance
  - **NO**
    - NFA

- **Are the criteria met for SCR?**
  - **YES**
    - Follow Chapter 8 guidance
  - **NO**
    - NFA

- **Follow Chapter 8 guidance**

- **No further action (NFA)**